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ABSTRACT

This final report describes activities and accomplishments of Alaska's 3-year program on services for children and youth with dual sensory impairments. The project provided technical assistance to local education agencies, infant learning programs, and other educators. It also provided support and training to families of children with deaf-blindness. Primary services provided by the project were technical assistance at community sites, consultation and training to parents, consultation and technical assistance to service providers throughout the state, support for transition planning, dissemination of information, and maintenance of census data on Alaskan children with deaf-blindness. Ongoing coordination and interagency collaboration occurred with public, private, local, and national resources. This report describes the project's conceptual framework and justification, goals and objectives, activities and accomplishments, problems, evaluation, and impact. Appendices include a listing of project library materials, results of satisfaction surveys, and samples of project-developed products (including a student referral packet, and information and screening forms concerning Usher's syndrome). (DB)

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ED 390 222

Alaska Services for Children and Youth With Dual Sensory Impairments

Final Performance Report
October 1, 1992 to September 30, 1995

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ABSTRACT

The Alaska Department of Education, through the Special Education Service Agency, provided single state service delivery for all children in Alaska who were identified as experiencing deaf-blindness. The project was titled "Alaska Services for Children and Youth with Dual Sensory Impairments (DSI)."

The project provided technical assistance to Local Education Agencies, Infant Learning Programs, and others responsible for educating children with deaf-blindness throughout the state of Alaska. It also provided support and training to the families of these children. This assured that children with deaf-blindness received effective infant, educational, vocational and transitional services.

Primary services provided by the project were technical assistance on-site in communities; consultation and training to parents; consultation and technical assistance to service providers throughout the state; support for transition planning; dissemination of information, and maintaining census data on Alaskan children with deaf-blindness. Ongoing coordination and interagency collaboration occurred with public, private, local, and national resources such as Teaching Research Assistance for Children Experiencing Sensory Impairments (TRACES), Helen-Keller TAC, Hilton/Perkins National Project, the Alaska State Department of Education, and the state's lead agency under Part H of IDEA.

Services provided in this project were accomplished through a subcontract with the Special Education Service Agency (SESA). SESA is a public agency providing educational services for children with low incidence handicaps throughout the state. In addition to the federal program for Children and Youth with Dual Sensory Impairments, SESA manages the Low Incidence Disabilities Outreach Program for the Alaska Department of Education, and two Alaska Infant Learning Program grants for statewide services. It also managed the deaf-blind Pilot for Alaska Students with Deaf-Blindness: Inclusion in Regular Classrooms (PALS) while that project was funded.

I. Conceptual Framework and Justification

Alaska is geographically the largest state in the United States. There are approximately two hundred eighty-five (285) communities widely scattered over 591,004 square miles. The largest city in the state is Anchorage, which encompasses one-half of the state's total population of approximately 500,000 residents. The other one-half of the population reside outside of the Anchorage area in small towns and villages scattered throughout the interior and along the coast.

Children with deaf-blindness reside in both urban and rural/remote areas of the state. Historically, approximately fifty percent of the children with deaf-blindness have lived in locations around the state as diverse and remote as Achiachak, English Bay, and Hydaburg since the provision of technical assistance to promote education of children with deaf-blindness in their home communities began.

The following factors present in Alaska necessitated the provision of services as proposed by this project:

Low Incidence of Children with Deaf-Blindness - Children with deaf-blindness occur in very low incidence throughout the state of Alaska. They live in rural, remote and urban areas of the state and attend local schools. When this grant was written, there were twenty-one students throughout Alaska who were deaf-blind. These twenty-one children resided in eight different communities and attended six different school districts. Three children were infants and did not attend school yet, but received educational services in their home setting through the State of Alaska's Infant Learning Programs.

Educational Services - All children with deaf-blindness in Alaska receive services under either Part B or Part H of the Individuals with Disabilities Education Act (IDEA), thus there was no need for this proposed project to provide direct services.

Socio-economic - Communities in Alaska contain a diverse mix of individuals with various cultural backgrounds which include the Native American population, Russians, immigrants from diverse parts of the world, and individuals who have moved here from other parts of the United States. Associated with these vastly differing cultures are corresponding variances in life styles, traditions, and economics. In developing educational/vocational training programs which will allow individuals with deaf-blindness to become more independent members of their unique societies, these variances preclude the possibility of centralized programming. The skills identified as necessary to survive within the various socio-economic groups were found to be heterogeneous in nature, and, therefore, required extremely individualized approaches.

Philosophy - It has been, and continues to be, the policy of the Alaska State Department of Education that, whenever possible, all students should be served within the geographical and cultural environments of their unique societies. This policy is stated in the Alaska State Plan of 1992-94. The state plan includes services provided through Part H of IDEA. Furthermore, the Department of Education is committed to serving children with deaf-blindness in their least restrictive environment as described by Public Law 94.142.

Professional Educational Opportunities - Because of the geographic separation of the state from the other forty-nine (49) states, and the separation among Alaskan communities due to the limited road accessibility, it is often difficult to attract and retain qualified teachers and other professionals to work with the children with deaf-blindness in both urban and rural areas of Alaska. Paraprofessionals tend to be local individuals from the community with varying degrees of education. These individuals remain in their positions for greater lengths of time.

There are no teacher education programs in Alaska which prepare teachers to work with children with deaf-blindness and expertise in deaf-blindness is extremely limited. Professionals and paraprofessionals working directly with children with deaf-blindness in local communities generally are not trained to provide education to these children and do not have access to others with this expertise. The distance of Alaska from the contiguous United States precludes the casual access to ongoing educational opportunities. Educational personnel need additional skills and must receive initial training as well as ongoing assistance in the education of children with deaf-blindness.

Transiency - Alaska experiences relatively high staff turnover, especially in rural areas. Qualified personnel with expertise in the field of the education of children with deaf-blindness are very seldom, if ever, found to fill these vacant positions. Staff trained by project personnel are replaced with inexperienced or untrained staff. Training, by necessity, became an ongoing function of the project.

II. Project Goal and Objectives

It has been, and continues to be, the policy of the Alaska State Department of Education that, whenever possible, all students should be served within the geographical and cultural environments of their unique societies. This policy is expressed in the Alaska State Plan of 1992-94 and includes services provided under Part H of IDEA.

The goal of this project was to coordinate already available services and provide technical assistance to parents, teachers, administrators, residential staff, and others providing educational services to children with deaf-blindness. This goal promoted the policy of the State Department of Education and ensured that the services provided promoted maximum accessibility to an appropriate education without regard to age, race, or location in the state.

The goal of this project was accomplished through the implementation of the following objectives and activities.

Objectives and Activities

Objective 1: To assure effective educational, vocational, transitional, and related services to Alaskan children with deaf-blindness.

Activity 1.1 To write Technical Assistance Agreements with all school districts and other agencies serving children with deaf-blindness based on individualized needs.

Activity 1.2 To assist Local Education Agencies and other educational/vocational service providers in conducting Child Study Team (CST) activities for children with deaf-blindness.

Activity 1.3 To assist Local Education Agencies and other educational service providers in developing effective prescriptive instruction in integrated and included settings.

Activity 1.4 To provide staff of Local Education Agencies and other educational/vocational service providers with required direct individualized technical assistance and follow-up.

Activity 1.5 To coordinate individualized transition planning for children with deaf-blindness.

Objective 2: To assure comprehensive and continuing diagnostic and evaluative services for Alaskan children with deaf-blindness.

Activity 2.1 To assure initial comprehensive assessments of each suspected child with deaf-blindness.

Activity 2.2 To review assessment data of suspected children with deaf-blindness and to recommend services.

Objective 3: To assure Alaskan children with deaf-blindness the benefit of trained professional, paraprofessional, and ancillary personnel.

Activity 3.1 To conduct individualized needs assessment with teachers, teaching assistants, and ancillary staff.

Activity 3.2 To conduct on-site training sessions and consultation to administrators, teachers, paraprofessionals, related service providers, and ancillary personnel.

Activity 3.3 To assure access to technical assistance and training available through state, federal, and private sources to those teaching children with deaf-blindness.

Objective 4: To provide consultative, training, and counseling services to families of children with deaf-blindness.

Activity 4.1 To provide individualized training, consultation, and counseling to families with children with deaf-blindness in their communities and to assist families in locating resources such as mental health agencies for in-depth counseling as needed.

Activity 4.2 To provide needed training, consultation, and counseling to parents of children with deaf-blindness in conjunction with statewide/national educational activities for parents.

Activity 4.3 To coordinate with federal Technical Assistance projects to provide training, consultation, and counseling to families.

Objective 5: To replicate successful, innovative approaches to providing educational or related services to children with deaf-blindness.

Activity 5.1 To provide inservice training and consultation for Local Education Agencies and other educational/vocational service providers serving children with deaf-blindness.

Activity 5.2 To disseminate best practices and procedures related to developed and refined teaching techniques and other information relevant to children with deaf-blindness monthly through the mail, SpecialNet, parent/teacher newsletters or personal contact.

Activity 5.3 To offer for publication and presentation those best practices and procedures identified.

Activity 5.4 To coordinate with the Inclusion Pilot Project.

Objective 6: To coordinate the location of Alaskan children with deaf/blindness and maintain the Deaf/Blind Census.

Activity 6.1 To coordinate location activities with state and Local Education Agencies' child find projects.

Activity 6.2 To maintain a state census for all children with deaf-blindness identified in Alaska.

Activity 6.3 To submit data annually to the Secretary of Education to meet requirements under P.L. 98-199.

Activity 6.4 To complete annual project evaluations and submit required reports to the project officer.

Objective 7: To provide services coordinated with Local Education Agencies and other state, regional, and federal agencies to children with deaf-blindness in Alaska.

Activity 7.1 To participate in state planning for the development of comprehensive educational services for young children with dual sensory impairments and their families.

Activity 7.2 To participate in state planning activities for preservice and inservice training for personnel responsible for teaching students with disabilities.

Activity 7.3 To assure a continuation of effective direct and indirect services to Alaskan children with deaf-blindness and their families.

Activity 7.4 To advocate for the needs of children with deaf-blindness with applicable local, state, and federal service providers.

Objective 8: To maintain an advisory board to disseminate information on, plan, and evaluate project activities.

Activity 8.1: Maintain an advisory board to include consumers and service providers.

Activity 8.2: Disseminate information regarding project activities to advisory board members.

Activity 8.3: Conduct a minimum of two and a maximum of four (yearly) advisory board meetings.

III. Project Activities and Accomplishments

Objective 1: To assure effective educational, vocational, transitional, and related services to Alaskan children with deaf-blindness.

Activity 1.1 Technical Assistance Agreements (TAA) were written with all school districts, Infant Learning Programs, or other agencies serving children with deaf-blindness based on individualized needs. In some districts, the TAA was written at the district level and in other districts the TAA was written per individual student. Project staff encouraged that a TAA be written with input from the child's service team including parents, teachers, and administrators whenever possible. The TAA was rewritten annually or upon receiving new referrals so they reflect the changing needs of the service providers and the children they served.

Activity 1.2 The Dual Sensory Impairment (DSI) Project assisted Local Education Agencies and other educational/vocational service providers in conducting Child Study Team (CST) activities for children with deaf-blindness. Each year the DSI program assisted in approximately seven CSTs, involving approximately 15-17 contacts. This included coordinating and facilitating future plans or MAPS sessions, providing assistance in developing appropriate education goals and objectives, and facilitating transition services. The outcome was that IEPs (Individual Education Plans), IFSPs (Individual Family Service Plans), and ITPs (Individual Transition Plans) reflected the unique needs of children with deaf-blindness.

Activity 1.3 Technical assistance to Local Education Agencies (LEA) and other educational service providers to develop effective prescriptive instruction in integrated and included settings was an ongoing grant activity. To accomplish this activity, assistance was provided to LEAs through a variety of forms of technical assistance.

Project staff shared information through ongoing mailings, phone contact, newsletters, and library resources. An average of two site visits yearly were provided to districts or programs serving students with deaf-blindness so that personalized needs and issues could be addressed. During each of the three years of the grant, the DSI project sponsored and provided trainings and/or courses at statewide conferences or academies, such as, the Statewide Special Education Conference, Pathways Conference, and the Summer Academy. Stipend assistance was available to families and service providers so they could attend such trainings and receive the information on effectively educating students with dual sensory impairments. Teachers serving students with deaf-blindness were also encouraged to present at conferences so that in-state expertise could be developed. Between workshops, conferences, disseminated information, and individualized site visits, even the most remote sites in Alaska received benefits from the range of assistance available.

Activity 1.4 Staff averaged two site visits per year to sites serving students with deaf-blindness. Site visits provided services which centered upon their defined needs in program development, modifications to individual education and instruction plans, or application of information acquired through dissemination of information on effective practices for children with deaf-blindness. In addition to direct site visits, distance delivery strategies were also used. For example, nationally known consultant, Dr. Deborah Chen,

provided technical assistance on communication through distance delivery, which directly helped four students and families and indirectly affected the programs of eight other students at the sites.

Activity 1.5 Project staff directly assisted in the coordination of transition services for approximately six students. Two students either transitioned or are preparing to transition out of school services into adult services. Transition planning from school services have included the student, family members, educational staff, vocational staff, advocates, and other service providers as appropriate. In addition, project staff had ongoing contact with Helen Keller Affiliate Program in Anchorage to facilitate coordination of services between the two projects. Three students transitioned from infant programs into school programs. One student transitioned into a more age-appropriate class and staff required extensive training and support in accomplishing this transition. In addition to the direct assistance in transition planning, the DSI Program, in collaboration with Helen Keller TAC, provided a course for credit at the Statewide Special Education Conference on *Transition Through the Ages*. Thirteen people attended, including a parent of a student who is preparing to transition out of school. To further assure that information was widely disseminated on the importance of transition planning, the theme for one of the DSI newsletters, *Keeping in Touch*, was transition. This newsletter was mailed to approximately 200 readers throughout Alaska and the Lower 48.

Objective 2: To assure comprehensive and continuing diagnostic and evaluative services for Alaskan children with deaf-blindness.

Activity 2.1 To assure initial comprehensive assessments of each suspected child with deaf-blindness, medical records and education records were reviewed by project staff of every child referred to the program. When the records appeared incomplete and the child was suspected of being deaf-blind, families and/or educational staff were contacted, consulted, and referred to medical specialists with experience in assessing children with sensory impairments. Program staff also trained and assisted service providers in providing functional or educational assessments appropriate for children with dual sensory impairments. Current materials for educational assessment were provided through the resource library with program staff available to assist in implementing the assessments.

Activity 2.2 As part of qualifying a student as deaf-blind, the DSI staff reviewed assessment data of suspected children with deaf-blindness. Based on that data, services were recommended to the family and/or service providers. No family or service provider who referred a child was left without some follow-up, albeit acceptance into the DSI program or a referral to another program.

Objective 3: To assure Alaskan children with deaf-blindness the benefit of trained professional, paraprofessional, and ancillary personnel.

Activity 3.1 Individualized needs assessments with teachers, teaching assistants, and ancillary staff were conducted in a variety of ways throughout the project. They were mailed to service providers. They were part of the Technical Assistance Agreement. They were part of the annual evaluation. Over the course of the grant, the most effective way for obtaining a meaningful needs assessment was through phone conversations or direct contact. Based on the needs assessments, TAAs were written and services provided that were personalized and meaningful to the staff's needs.

Activity 3.2 On-site visits, ranged from 1-3 visits per year. These visits impacted every student with deaf-blindness served by the district as the site visits were based on the expressed needs of the districts. Sites served during the course of the grant included

Anchorage, Fairbanks, Juneau, Hydaburg, Bethel, Sitka, Homer, Akiachak, and Matanuska-Susitna. After each visit, a written report summarizing the consultation visit was sent to families, administrators, teachers, and ancillary personnel. In addition to providing consultation about the student needs, on-site trainings were provided, as requested by the district. A sampling of the training topics included:

- inclusion
- MAPS and future planning
- literacy
- Usher syndrome and screening
- communication development
- teaching strategies
- assessment
- disability awareness

Activity 3.3 Throughout the grant, the DSI project coordinated and collaborated in providing technical assistance and training to those teaching children with deaf-blindness through state, federal, and private sources. The outcomes from these trainings better prepared families and service providers in meeting the needs of children with deaf-blindness. The following is a sample of the activities provided and the collaborating agencies.

Activities	*Collaborating Agencies*
Winners All: Providing Services to Students with Dual Sensory Impairments (Summer Academy)	TRACES Alaska Department of Education
Usher Training Course	TRACES
Lifelong Transitions (Special Education Conference)	TRACES Helen Keller TAC
Orientation and Mobility (Special Education Conference)	TRACES Helen Keller TAC Alaska Department of Education CSPD (Comprehensive System for Personnel Development))
Planning Today for Tomorrow: A Planning Session for Families of Children with Dual Sensory Impairments (Pathways Conference)	Hilton-Perkins P.A.R.E.N.T.S., Inc., Alaska

Objective 4: To provide consultative, training, and counseling services to families of children with deaf-blindness.

Activity 4.1 The project staff met and directly worked with nearly all of the families when providing site visits in their communities. As part of the project's procedures when preparing for a site visit, families were contacted and if the parent desired, a family visit was held. Alternative forms of contact were also available through teleconferencing, phone calls, mailings, written reports, and newsletters. A *Parent Resource Guide* was developed

including local and national resources, which was given to families as they initially began the program.

Activity 4.2 *Training and consultation* was available to parents of children with deaf-blindness in conjunction with statewide/national educational activities for parents. Every other year, the state Pathways Conference is held. This conference is specifically designed for parents of children with disabilities and occurred once during the grant. Six family members and two children attended the conference. Three workshops were organized by the DSI project which specifically addressed deaf-blindness. A social was also held in collaboration with Alaska National Association for Parents of Children with Visual Impairments. During the two years when Pathways did not occur, a total of eight families were sent out-of-state to attend family retreat weekends. This activity directly impacted families by providing them with the opportunity to meet others, both locally and nationally, who shared similar issues and concerns.

Activity 4.3 Throughout the grant, the DSI project coordinated with federal Technical Assistance projects to provide training, consultation, and counseling to families. Examples of such coordination and collaboration included the course offered on *Lifelong Transitions* during the Special Education Conference. Helen Keller TAC provided assistance in identifying an appropriate presenter and providing funding assistance. The DSI project fully supported a parent of a young man who is preparing for transition to attend the course. The DSI project also coordinated closely with TRACES in providing trainings and consultations. Such coordination and collaboration with federal technical assistance projects assured that families were receiving and had access to current information from national sources.

Objective 5: To replicate successful, innovative approaches to providing educational or related services to children with deaf-blindness.

Activity 5.1 Inservice training and consultation for Local Education Agencies and other educational/vocational service providers serving children with deaf-blindness occurred throughout the grant. Each year during the grant at conferences such as the Statewide Special Education Conference, Pathways Conference, and Summer Academy, trainings and workshops were coordinated by the DSI project. These trainings used both local and national speakers to share their expertise and enabled service providers to glean current information on effective practices for educating students with deaf-blindness. Examples of such trainings and workshops included:

- Early Communication Using Switches
- Innovative Methods and Materials: Developing The Full Potential of Infant, Preschool Multiply Impaired Blind and Visually Impaired Children
- Orientation and Mobility for Individuals with Severe Needs and/or Deaf-Blindness
- Planning for the Future in Deaf-Blindness
- Usher Syndrome
- Inclusion Realized: A Student Who Is Deaf-Blind in an Early Childhood Education Program
- Students with Deaf-Blindness in a Village Setting
- Lifelong Transitions for Persons with Deaf-Blindness
- Orientation and Mobility: What Is It In Early Years?
- The Tool of Independent Travel for Children with Dual Sensory Impairments
- Winners All: Providing Services to Children with Dual Sensory Impairments

Activity 5.2 Best practices and procedures related to developed and refined teaching techniques and other information relevant to children with deaf-blindness were disseminated through mailings, newsletters, or other personal contact. Project staff produced two newsletters during each year of the grant which contained topical information as well as general information on effective practices for children with deaf-blindness. The project had an extensive lending resource library available for families and service providers (see Appendix A.) In addition, monthly mailings containing information from Special-Net, newsletters, and journals were mailed regularly to each district served by the project. Additional mailings and phone contact occurred per individual needs.

Activity 5.3 A presentation was given at the Project Directors' Meeting in October 1992 on effective distance delivery strategies for deaf-blind students in Alaska. During the remaining grant years poster presentations were provided each year at the Project Directors' Meeting. Another presentation was made during the poster session at the '92 National TASH Conference in San Francisco. This poster presentation was called *Developing Expressive Communication in Young Children with Dual Sensory Impairments: A Technical Assistance Project in Alaska.* Information from this presentation was also placed on the Special Net Deaf-Blind Bulletin Board in December 1992.

Activity 5.4 The PALS Inclusion Pilot Project and the DSI Project coordinated closely throughout the grant. Examples of such coordination and collaboration included regularly scheduled meetings between the staff, a shared advisory board, regular contributions to the DSI newsletter from the PALS staff, and team site visits. Coordination and collaboration between projects were both necessary and beneficial as there was an overlap of sites served between the two projects and staff needed to coordinate with each other in providing effective services. Also, each project member had different expertise. Through collaborating between projects, the sites served benefited from shared expertise and resources.

Objective 6: To coordinate the location of Alaskan children with deaf/blindness and maintain the Deaf/Blind Census.

Activity 6.1 Throughout the grant, activities were conducted to ensure the location of all children with dual sensory impairments in the state. Each year the project issued letters to all school district special education directors, coordinators of Infant Learning Programs, and later expanded to include pediatricians. This mailing included a project brochure, information related to the definition of dual sensory impairment, and eligibility for services from the project. Full referral packets were also disseminated annually at the Special Education Directors' Meeting. Presentations regarding the DSI project services were also made at this meeting, as well as at the Statewide Infant Learning Program Meeting.

Activity 6.2 The DSI project maintained the census for all children with deaf-blindness (birth through 21 years) identified in Alaska as evidenced by its annual reporting of this information to TRACES. Letters and census forms were sent to each of the districts or programs who reportedly served children with deaf-blindness. Information was collected to update the data on all children listed on the census . This information included age, sex, etiology, degree of vision and hearing loss, other handicapping conditions, setting of service, and P.L. 94-142, P.L. 89-313, or Part H reporting.

Activity 6.3 Data was submitted annually and in a timely manner to the Secretary of Education to meet requirements under P.L. 98-199.

Activity 6.4 All annual project evaluations and required reports to the project officer were submitted as required.

Objective 7: To provide services coordinated with Local Education Agencies and other state, regional, and federal agencies to children with deaf-blindness in Alaska.

Activity 7.1 During the grant, DSI staff coordinated with other state agencies in planning for the development of comprehensive educational services for young children with dual sensory impairments and their families. One of the major accomplishments was the collaboration and coordination which occurred between the DSI project and the State Infant Learning Program (ILP), which provides Part H services to infants and toddlers, including those with dual sensory impairments. Throughout the first two years of the grant, ongoing contact was made with the State ILP office regarding the collaboration of services. Awareness presentations were also provided at the annual State ILP Conference. In the final year of the project, collaborative planning between the ILP Program and the DSI Project, with financial assistance from the State National Diffusion Network, resulted in INSITE Training during FY 96 for ILP teachers and teachers serving young children with deaf-blindness.

Activity 7.2 DSI project staff participated in state planning activities for preservice and inservice training for personnel responsible for teaching students with disabilities as evidenced by the project supervisor becoming a committee member of the Comprehensive System for Personnel Development (CSPD). The project also received funding through CSPD, in association with Alaska Association for the Education and Rehabilitation for the Blind and Visually Impaired (Alaska AER) to sponsor a training on orientation and mobility during the 1994 Statewide Special Education Conferences. By coordinating state resources, more trainings were available to personnel serving children with dual sensory impairments.

Activity 7.3 Throughout the grant, DSI staff assured a continuation of effective direct and indirect services to Alaskan children with deaf-blindness and their families as they transitioned between services, including transitions from infant learning programs to school districts, and as they transitioned from school services to adult services. By being actively involved in IFSP or ITP planning meetings, staff provided direct assistance to approximately five students who either transitioned into the school district or transitioned out of the school district . With DSI services continuing until students are 22 years of age, the project was able to assure the continuation of information as students transitioned, moved, or changed classes.

Activity 7.4 Throughout the grant, project staff advocated for the needs of children with deaf-blindness with applicable local, state, and federal service providers. Information on the needs of children with dual sensory impairments were routinely disseminated at every site contacted. A newsletter was produced twice a year which contained information advocating the needs of children with dual sensory impairments and included resources for further advocacy information, such as the National Coalition for Deaf-Blindness. The outcome of this activity was to keep families and service providers informed about the unique needs of children with deaf-blindness and provide them with access to other local and national resources.

OBJECTIVE 8: To maintain an advisory board to disseminate information on, plan, and evaluate project activities.

Activity 8.1: An advisory board was maintained and included consumers, parents, and service providers. During the grant, bylaws were written to formalize and clarify the advisory board's function, membership, and regulations. As a result, the advisory board had a more defined and active role in assisting the project.

Activity 8.2: Throughout the grant, information was disseminated to advisory board members on approximately a monthly basis during the school year. Monthly mailings summarized the project's activities. Agendas and minutes were mailed before and after each of the board meetings. This resulted in keeping the board actively informed regarding the project.

Activity 8.3: Two advisory board meetings were conducted during each year of the grant. Input was provided to the DSI project as to issues discussed and the board remained informed of the project's activities and accomplishments.

IV. Problems

Identification -The number of children identified as deaf-blind in Alaska is low and has been below the expected count. The following annual census counts include the expected ranges of children with deaf-blindness in Alaska compared to the actual number.

Year	Number	+1SD	Expected	-1SD
1992	21	38	31	23
1993	16	38	31	23
1994	20	52	36	20

Efforts to assure that all children in Alaska with deaf-blindness were referred to the DSI Project included revising the referral packet, expanding mailings to include pediatricians, and coordinating and collaborating with the state ILP Program. At the completion of this grant, there were 22 children with deaf-blindness identified.

Budget - Throughout the grant the project remained at level funding. To maintain a sufficient budget for service activities when overall expenses continued to increase, personnel FTE was reduced. As a result, providing services at the same level with reduced staff was a challenge.

Transiency - Alaska experiences a relatively high turnover, especially in rural areas. Staff trained by project personnel would frequently be replaced with untrained staff. This necessitated ongoing training, often at a basic, introductory level.

Limited Expertise - There is limited deaf-blind expertise in Alaska. Those with training were either involved with this project or employed full time in school districts. Those with deaf-blind expertise were utilized by serving on the DSI Advisory Board, presenting at statewide conferences, or providing their classrooms as model sites for other service providers.

Parent Groups - Due to the limited number of children with deaf-blindness in Alaska and the size of the state, there is no parent group specific for parents of children with deaf-blindness. Instead, parents were encouraged to become involved with Alaska National Association for Parents of Children with Visually Impairments (AK-NAPVI). The DSI Project worked closely with AK-NAPVI is assuring that parents of children with deaf-blindness were informed and included in their activities such as the parent teleconferencing sessions, socials and meetings during Pathways.

V. Evaluation

Workshops and Trainings: Numerous grant sponsored workshops occurred throughout the grant. These workshops were presented by project staff, professionals from Alaska, and professionals from outside of Alaska. With few exceptions, workshops were evaluated to determine effectiveness. Although different evaluations were occasionally used, the most predominant form was the *Workshop Evaluation Scale* (McCallan, E.). This scale included seven items that were rated on a Likert scale from 1 (poor) to 7 (excellent). The items are as follows:

1. The organization of the workshop was...
2. The objectives of the workshop were...
3. The work of the presenter was...
4. The ideas and activities of the workshop were...
5. The scope was...
6. My attendance at this workshop should prove...
7. Overall, I consider this workshop...

The following chart summarizes a sample of the workshop evaluations.

Summary of Workshop Evaluations by Workshop Topics

Mean Responses

Workshop	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7
Orientation & Mobility	6.5	6.5	6.6	6.6	6.6	5.8	6.5
Inclusion in a Village	6.3	6.7	6.4	6.3	6.	5.9	6.1
Inclusion Realized	6.5	6.6	6.6	6.5	6.4	6.3	6.4
Lifelong Transitions	6.6	6.4	6.6	6.4	5.9	6.4	6.5
Usher Syndrome	6.3	6.3	6.3	6.1	6.1	6.3	6.
Usher Syndrome: What Is It?	5.7	6.3	5.8	5.8	5.8	6.	5.8
Usher Screening	6.9	6.7	6.9	7.	6.9	6.9	6.8

As indicated, the workshops sponsored by the DSI Projects were viewed very favorably. These workshops were attended by teachers, related service providers, parents, and administrators.

Annual Satisfaction Surveys: At the end of each year, satisfaction surveys were sent to parents and service providers who received technical assistance. In an effort to acquire more useful information and increase the return rate, the surveys continued to be revised annually. In the final

year of the grant, a separate survey was developed for parents as many of the questions asked on the service provider survey were not germane to parents. As noted in the following chart, revising the survey forms appeared to increase the response rate.

Response Rate to the Annual Satisfaction Survey

Year	Parent	Admin	Sped Teacher	Reg Ed Teacher	Related Service	Aide	Total
1993	4	1	4		1		10
1994	4	1	6		1		12
1995	8	3	6	1	5	1	24

Results from the 1995 Parent Satisfaction Survey and the School District, Infant Learning Programs and agencies can be found in the Appendix B. Overall, the responses appeared very positive. In those few situations where parents or service providers expressed concerns, this was viewed as an opportunity to follow-up, clarify and remediate the issues.

VI. Project Impact

During the grant, various products were developed and widely disseminated, as indicated in the following table. Some of these products were a collaborative effort with other projects. Copies of these products are in the Appendix C.

Product	Intended Audience	Dissemination	Outcome
Brochure*	Families Service providers	Distributed in Alaska to families and service providers through mailings, at meetings, and at conferences Distributed nationally to service providers at meetings and conferences	Project awareness Referral information Deaf-blind information
Usher Pamphlet**	Families Service providers	Distributed in Alaska and nationally at workshops and trainings	Awareness of Usher Syndrome Screening tool for Usher Syndrome
Newsletter	Families Service providers	Mailed to approximately 150 families and service providers in Alaska and nationally	Information dissemination about project and issues in deaf-blindness
Referral Packet	Families Service providers ILP coordinators	Distributed in Alaska to all special education directors, other service providers, and families upon referral	Project information Referral information and forms
Family Resource Guide	Families	Given to families upon referral/acceptance to project	Resource information

*collaborative effort with TRACES
**collaborative effort with Deaf-Blind Affiliate Program

VII. Additional Information

Further information regarding this project can be found by contacting:

Alaska Dual Sensory Impairment Project
Special Education Service Agency
2217 East Tudor Road, Suite 1
Anchorage, Alaska 99501
(907) 562-7372 V
(907) 563-8284 TTY

This is to assure that a copy of this final report was sent to:

ERIC Clearinghouse
Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(800) 328-0272 V
(703) 620-3660 V/TTY

Appendix A

Library Materials

Using The SESA Library

The SESA Library was established for the use of SESA staff and clients. Materials are loaned out so that clients can review them and decide if they are appropriate to order for themselves. The SESA Library also lends out materials purchased under an Assistive Technology grant, which are available to anyone in the state. In addition, the Library manages the loans of some long term loan items purchased under another grant.

The Library has books, videos, software, assessments, sound recordings and equipment available. The equipment covers a variety of special needs. It includes magnifiers, sensory stimulation materials, switches, computer peripherals, braille and low vision materials, battery operated toys, games, instructional materials, tape recorder/players, braille writers and other items. Due to the large number of items, a complete catalog isn't practical. However, if you call with a specific question (for example, sign language videos), a list can be generated and sent out to you.

The library has a variety of information sources. Call if you have questions. Sometimes you will be referred to your local library or another source.

TERMS OF LOAN

With the exception of the long term loan grant and APH items, all materials are loaned for a period of thirty days. If no one has requested the item, the loan may be renewed. However, once another person has requested an item, you must return it. You have no guarantee of more than thirty days. Usually, this is adequate time to evaluate the item's usefulness.

HOW TO CHECK THINGS OUT

You can borrow things by mail or phone request, or you can come by the library. Since library hours vary, call before coming by.

You will need to leave your name, address, phone number and an alternate phone number, so that we can reach you if necessary. Starting in 1994/95, library users will need to sign a Memorandum of Agreement. This says that you are willing to take responsibility for the materials, and will return them when they are due. For school districts, this form must be signed by the principal at each site. For other programs, the form must be signed by the director. For individuals, the individual signs.

You will be given or sent a transmittal form along with the materials. If the materials were mailed to you, you will receive a second copy of the transmittal form, folded and with SESA's address stamped on it. You must sign that copy, put a stamp on it, and drop it in the mail. This is so we know the materials were received. It gives us some peace of mind that materials aren't lost in the mail. Take a minute to read the transmittal form. The library policy is on the back. You will be held to all terms of use. Keep this form so you have a list of what is checked out to you and when they are due to be returned.

HOW TO RETURN ITEMS

You may bring the items by Monday through Friday, eight a.m. to 4:30 p.m., or you may mail items back. Be sure that all parts of each items are returned. If mailing materials, pack them carefully. If there is a note on the transmittal form about insuring the item when it is returned, be sure to do that.

IF YOU DON'T RETURN ITEMS

Overdue notices are mailed out monthly. If you haven't called to renew, you will receive one. If you get an overdue notice, do not ignore it. Call or write to see if you can extend the loan, or else return the item(s) immediately. If there is a note on the notice indicating that someone else is waiting for the item, have the courtesy to return the item promptly. Remember, the loan was made so that you could evaluate the item(s) for possible purchase, NOT for long term use. Should you persistently ignore overdue notices, you will be billed for the item. We are discussing the possibility of turning names over to a collection agency or reporting to a credit agency. This could affect your credit rating. No kidding. The library can only make many items available to many people if they all come back. We save schools and families thousands of dollars in purchases each year. It isn't unreasonable to expect that users will respond to notices, return materials promptly, and otherwise behave responsibly.

REMEMBER:

- Length of loan is thirty (30) days. We will be as flexible as we can IF you call to discuss the matter.
- Do not ignore overdue notices. Call or write for permission to renew, or else return the item promptly. Non-responsiveness will result in a bill for the item(s).
- Keep all packing materials for returning the item.
- Keep all manuals, cables, parts, etc., with the item. The item will remain checked out to you until all parts are returned. You may be billed for missing parts.
- Treat the item with care. Damage may result in a bill.

Question? Concerns? Please call: Special Education Service Agency (907) 562-7372
2217 E. Tudor Road, Suite 1 (907) 562-0545 (FAX)
Anchorage, AK 99507 (907) 563-8284 (TT)

SPECIAL EDUCATION SERVICE AGENCY

LIBRARY

MATERIALS BELONGING TO THE DUAL SENSORY IMPAIRED PROGRAM

Type	Vis Mat
Call	371.912/BRING
Main	Cooley, Elizabeth
Title	Bringing out the best [videorecording] : encouraging expressive communication in] children with multiple handicaps
Auth Stat	Elizabeth Cooley

Type	Vis Mat
Call	371.393/Marone
Main	Marone, Frank
Title	Essential considerations in analyzing challenging behaviors [videorecording] : comprehensive, detailed programming to overcome challenging behaviors
Auth Stat	Frank Marone

Type	Book
Call	371.904/Evans
Main	Evans, Ian M
Title	An educative approach to behavior problems
Auth Stat	Ian M. Evans

Type	Book
Call	618.928/Ferry
Main	Ferry, Peggy C
Title	Seizure disorders in children
Auth Stat	Peggy C. Ferry

Type	Book
Call	618.92/Hyvari
Main	Hyvarinen, Lea
Title	Vision in children : normal and abnormal
Auth Stat	Lea Hyvarinen

Type	Book
Call	362.41/Hill
Main	Hill, Everett W
Title	Orientation and mobility techniques : a guide for the practitioner
Auth Stat	by Everett W. Hill and Purvis Ponder

Type	Book
Call	370.154/Blum
Main	Blum, Gloria
Title	Feeling good about yourself : a guide for people working with people who have disabilities or low self-esteem
Auth Stat	Gloria Blum

Type	Book
Call	649.1/511/Dodson
Main	Dodson-Burk, Bonnie
Title	Orientation and mobility primer for families and young children
Auth Stat	Bonnie Dodson-Burk and Everett W. Hill

Type	Book
Call	305.908/161/Communi
Title	Communication development in young children with deaf-blindness : literature review I
Auth Stat	edited by Michael Bullis

Type	Book
Call	362.41/McInne
Main	McInnes, J. M. (John M.)
Title	Deaf-blind infants and children : a developmental guide
Auth Stat	J.M. McInnes, J.A. Treffry

Type	Vis Mat
Call	616.855/New
Title	New CONCEPT videodisc [videorecording]
Auth Stat	Teaching Research and Utah State University

Type	Book
Call	616.855/New
Title	New CONCEPT videodisc training manual : communication options for nonspeaking children : essentials for parents and teachers
Auth Stat	a product of the Communication Skills Center for Young Children with Deaf-Blindness

Type	Book
Call	419/Gustas
Main	Gustason, Gerilee
Title	Signing exact English
Auth Stat	by Gerilee Gustason, Donna Pfetzing, Esther Zawolkow ; illustrations by Carolyn B. Norris ; foreword by Hilde Schlesing

Type	Book
Call	362.41/INSITE
Main	Watkins, Susan
Title	Developing sign communication with the multi-handicapped sensory impaired child : handbook to accompany the INSITE Communication Program on the Development of Primitive, Co-active and Interactive Signi
Auth Stat	Susan Watkins ; photographer, Ted Hanson

Type	Book
Call	362.41/Smith
Main	Smith, Audrey J
Title	Look at me : a resource manual for the development of residual vision in multiply handicapped children
Auth Stat	Audrey J. Smith, Karen Shane Cote

Type	Book
Call	305.908/161/092/Yoken
Main	Yoken, Carol
Title	Living with deaf-blindness : nine profiles
Auth Stat	developed and written by Carol Yoken

Type	Book
Call	362.41/Freema
Main	Freeman, Peggy
Title	Understanding the deaf/blind child
Auth Stat	Peggy Freeman

Type	Book

Call	362.41/Bolton
Main	Bolton, Sharon
Title	One step at a time : a manual for families of children with hearing and vision impairments
Auth Stat	written by Sharon Bolton ; edited by Kris Stom Williamson

Type	Book
Call	371.9/Schur/Vol. 3
Main	Schur, Sally L
Title	Basic life skills training guides for the deaf-blind and severely handicapped : volume 3 : personal management
Auth Stat	by Sally L. Schur ... [et al.] ; prepared for South Central Regional Center for Services to Deaf-Blind Children

Type	Book
Call	371.9/Schur/Vol. 5
Main	Schur, Sally L.
Title	Basic life skills training guides for the deaf-blind and severely handicapped : volume 5 : home management
Auth Stat	by Sally L. Schur ; prepared for South Central Regional Center for Services to Deaf-Blind Children

Type	Vis Mat
Call	302.222/Tangib
Title	Tangible symbol systems for individuals with multi-sensory impairments [videorecording]
Auth Stat	Charity Rowland, Philip Schweigert

Type	Book
Call	302.222/Rowlan
Main	Rowland, Charity
Title	Tangible symbol systems : symbolic communication for deaf-blind children and youth : final report, October 1, 1985-December 31, 1987
Auth Stat	principal investigator, Charity Rowland ; intervention coordinator, Philip Schweigert ; research assistant, Betty Brumm

Type	Book
Call	371.911/Learni
Title	Learning steps : a handbook for persons working with deaf-blind children in residential settings
Auth Stat	prepared under the sponsorship of the Southwestern Region Deaf-Blind Center, California State Department of Education a

Type	Book
Call	419/Sign
Title	Sign language curricula

Type	Book
Call	688.72/Burkha
Main	Burkhart, Linda J
Title	Homemade battery powered toys and educational devices for severely handicapped children
Auth Stat	Linda J. Burkhart

Type	Book
Call	688.72/Burkha
Main	Burkhart, Linda J
Title	More homemade battery devices for severely handicapped children with suggested activities

Auth Stat	Linda J. Burkhart
Type	Book
Call	649.151/Parent
Title	Parenting the handicapped child : a compilation of materials for natural and foster parents of handicapped children
Auth Stat	compiled by the Deinstitutionalization Model for Deaf-Blind Children and Youth, Teaching Research ; Nancy Johnson-Dorn,
Type	Book
Call	371.26/Assess
Title	Assessment tools for use with the severely multiply handicapped-deaf/blind
Type	Book
Call	649.122/Brazel
Main	Brazelton, T. Berry, 1918-
Title	Infants and mothers : differences in development
Auth Stat	T. Berry Brazelton ; foreword by Jerome S. Bruner
Type	Book
Call	331.591/0973/Employm
Title	Employment options for young adults with deaf-blindness : philosophy, practice, new directions
Auth Stat	Steven S. Barrett, Anne M. Smith, editors
Type	Vis Mat
Call	371.904/Barnes
Main	Barnes, Ellen B
Title	Integration can work [slide] : a case study of a learning environment : a slide presentation
Auth Stat	by Ellen B. Barnes, Peter Knoblock
Type	Vis Mat
Call	616.855/Touch
Title	Touch cues [videorecording]
Auth Stat	with Cindy Funk ... [et al.]
Type	Book
Call	371.904/Levin
Main	Levin, Jackie
Title	Fun for everyone : a guide to adapted leisure activities for children with disabilities
Auth Stat	Jackie Levin and Kathy Enselein
Type	Book
Call	615.85/154/Wacks
Main	Wacks, Karen S
Title	Music therapy activities for use with developmentally disabled individuals
Auth Stat	developed by Karen S. Wacks, Janis L. Johnson, Patricia DiGiulio
Type	Book
Call	616.855/Wilcox
Main	Wilcox, M. Jeanne
Title	Strategies and methods for enhancing functional communication skills
Auth Stat	M. Jeanne Wilcox, Juli Baumgarner
Type	Book
Call	616.855/Wilcox
Main	Wilcox, M. Jeanne
Title	Guidelines for obtaining ecologically-based communication assessments

Auth Stat	M. Jeanne Wilcox
Type	Book
Call	617.8/Flexer Flex Guid
Main	Flexer, Carol
Title	Guidelines for determining functional hearing in school-based settings
Auth Stat	Carol Flexer, Kathleen Shelby, M. Jeanne Wilcox (editor)
Type	Book
Call	612.84/Campbe
Main	Campbell, Philippa H
Title	Guidelines for determining functional use of vision in school-based settings
Auth Stat	Philippa H. Campbell, Juli Baumgarner, M. Jeanne Wilcox (editor)
Type	Book
Call	616.855/Skowro
Main	Skowron-Gooch, Annette
Title	Communication assessment procedures for students with severe and multiple handicaps
Auth Stat	by Annette Skowron-Gooch
Type	Book
Call	616.855/Callie
Title	The Callier-Azusa scale
Auth Stat	Robert Stillman (editor) and Christy Battle ... [et al.]
Type	Book
Call	362.428/Clark
Main	Clark, Thomas C
Title	The Ski*Hi model : programming for hearing impaired infants through home intervention : home visit curriculum
Auth Stat	Thomas C. Clark and Susan Watkins
Type	Book
Call	371.911/Accept
Title	Accepting individual differences, AID : visual impairment
Type	Book
Call	617.8/Regenb
Main	Regenbogen, Lucian S
Title	Oculo-auditory syndromes
Auth Stat	Lucian S. Regenbogen, Gabriel J. Coscas
Type	Vis Mat
Call	612.84/How
Title	How do we see?
Auth Stat	produced by the Ski*Hi Institute ; direction, Sue Watkins ; production, Earl Rouse
Type	Book
Call	362.404/Jaeger
Main	Jaeger, D. LaVonne
Title	Transferring and lifting children and adolescents : home instruction sheets
Auth Stat	by D. Lavonne Jaeger with Joan Hewitt Gertz ... [et al.] ; illustrations by Janis Atlee and Richard Penhell
Type	Book
Call	615.822/Drehob
Main	Drehoble, Kathy Fleming
Title	Pediatric massage for the child with special needs

Auth Stat	Kathy Fleming Drehobl, Mary Gengler Fuhr ; forewords by Shereen D. Farber and Melvin L. Morse ; illustrations drawn und
Type	Vis Mat
Call	371.911/Decidi/Pt. 1
Title	Deciding what to teach at home [videorecording] : part 1
Auth Stat	Debra Chen
Type	Vis Mat
Call	371.911/Decidi/Pt. 2
Title	Deciding what to teach at home [videorecording] : part 2
Auth Stat	Debra Chen
Type	Book
Call	362.41/INSITE/V. 1
Title	A Manual for parent advisors to accompany INSITE curriculum manuals
Auth Stat	editor, Elizabeth C. Morgan
Type	Book
Call	362.41/INSITE/V. 2
Title	Parent discussions
Auth Stat	editor, Elizabeth C. Morgan
Type	Book
Call	362.41/INSITE/V.3
Title	Communication
Type	Book
Call	362.41/INSITE/V.4
Title	Developmental skills manual
Auth Stat	editor, Elizabeth C. Morgan
Type	Book
Call	362.1/968/Functio
Title	Functional skills training for day to day care of developmentally disabled individuals : a guide for respite care workers & parents
Auth Stat	by Mary Ellen Sloan ... [et al.]
Type	Book
Call	615.5/Resour
Title	A Resource handbook for physical and occupational therapists in educational settings
Auth Stat	developed by the Committee for Physical Therapists in Educational Settings, Kansas Chapter, American Physical Therapy A
Type	Vis Mat
Call	419/Coacti/3,4
Title	A Coactive sign system for deaf-blind children [videorecording] : Lesson 3 : Daily routines; eating ; Mini lesson 3: Deciding which coactive signs to use first ; Lesson 4 : Daily routin
Auth Stat	directors, Paula Pitman, Sue Watkins ; SKI*HI Institute, Dept. of Communication Disorders, Utah State Universitu
Type	Book
Call	649.151/Ferrel
Main	Ferrell, Kay Alicyn
Title	Reach out and teach : reachbook : meeting the training needs of parents of visually and multiply handicapped young children
Auth Stat	by Kay Alicyn Ferrell ; with contributions by Sherrill Butterfield, Zofja Jastrzembska,

Kristen Rapsher

Type Vis Mat
Call 362.41/We
Title We can do it together [videorecording] : mobility for students with multiple impairments
Auth Stat produced by Elga Joffee ; narrated by David Devan ; American Foundation for the Blind ; City of New York, Board of Educ

Type Vis Mat
Call 618.92/Coacti Coac
Title Coactive movement [videorecording] ; Touch cues

Type Book
Call 401.93/Tonels
Main Tonelson, Steve
Title Instruction manual for the Ski*Hi language development scale : assessment of language skills for hearing impaired children from infancy to five years of age
Auth Stat by Steve Tonelson and Susan Watkins

Type Book
Call 362.41/Bolton
Main Bolton, Sharon
Title One step at a time : a manual for families of children with hearing and vision impairments
Auth Stat written by Sharon Bolton ; edited by Kris Stom Williamson

Type Book
Call 371.9/Jakos
Main Jakos, Margritta
Title Handbook for teachers of behavior problem students
Auth Stat by Magritta Jakos and Merri Rowe

Type Book
Call 331.591/0973/Employm
Title Employment options for young adults with deaf-blindness : philosophy, practice, new directions
Auth Stat Steven S. Barrett, Anne M. Smith, editors

Type Book
Call 371.911/Indivi
Title Individualized curriculum sequence and extended classroom models for learners who are deaf and blind
Auth Stat by Edwin Helmstetter ... [et al.]

Type Book
Call 362.41/Value
Title Value-based services for young adults with deaf-blindness
Auth Stat Angela M. Covert and Theresa S. Carr, editors

Type Book
Call 155.85/Behavi/V. 3
Main Hall, R. Vance
Title Behavior modification : applications in school and home
Auth Stat R. Vance Hall

Type Book
Call 155.85/Behavi/V. 4
Main Panyan, Marion C

Title	New ways to teach new skills : a manual for teachers, parents and trainers of the retarded
Auth Stat	Marion C. Panyan

Type	Book
Call	694.1/511/Esche
Main	Esche, Jeanne
Title	A handbook for parents of deaf-blind children
Auth Stat	Jeanne Esche, Carol Griffin

Type	Book
Call	371.911/Robbins
Main	Robbins, Nan
Title	Educational beginnings with deaf-blind children
Auth Stat	by Nan Robbins

Type	Book
Call	371.911/Gothel Goth Work
Main	Gothelf, Carole R
Title	Working with students who have dual sensory impairments and cognitive disabilities : a handbook for special education teachers and related services personnel
Auth Stat	Carole R. Gothelf, Catherine H. Rikhye and Rosanne K. Silberman

Type	Book
Call	371.911/Robbin
Main	Robbins, Nan
Title	The deaf-blind "rubella" child : descriptive characteristics of children with auditory-visual impairments resulting from maternal rubella during pregnan
Auth Stat	by Nan Robbins, Gertrude Stenquist

Type	Book
Call	362.41/Guldag
Main	Guldager, Virginia
Title	Body image and the severely handicapped rubella child
Auth Stat	by Virginia Guldager

Type	Book
Call	401.93/Manual
Title	Manual for language development : a handbook of strategies for teaching children whose communicative skills range from non-responsiveness to use of acade
Auth Stat	edited by Tom W. Jones

Type	Book
Call	362.41/Perfor
Title	Performance guide for intervenors working with the deaf-blind

Type	Book
Call	371.911/Progra
Title	Program review and planning guide for the education of deaf-blind students
Auth Stat	edited and coordinated by Maurine Otos

Type	Book
Call	153.85/Use
Title	Use of aversive procedures with persons who are disabled : an historical review and critical analysis
Auth Stat	Doug Guess ... [et al.]

Type	Book

Call 153.85/Behavi
Title Behavior management and community integration for individuals with developmental disabilities and severe behavior probl
Auth Stat sponsored by the Office of Special Education and Rehabilitative Services and Research and Training Center on Community-

Type Book
Call 371.911/Venn
Main Venn, John
Title Systematic approach to adult placements (SAAP) : a referral guide for parents and special educators
Auth Stat developed by the Deaf-Blind Independent Living Project ; written by John Venn and Frank Wadler

Type Book
Call 649.151/Ferrel
Main Ferrell, Kay Alicyn
Title Reach out and teach : parent handbook : meeting the training needs of parents of visually and multiply handicapped young children
Auth Stat by Kay Alicyn Ferrell ; with contributions by Sherrill Butterfield, Zofja Jastrzembska, Kristen Rapsher

Type Book
Call 362.41/Functi
Title Functional skills screening inventory : an instrument to assess critical living and working skills : user's guide : print edition
Auth Stat Heather Becker ... [et al.]

Type Book
Call 362.41/Functi
Title Functional skills screening inventory : an instrument to assess critical living and working skills
Auth Stat Heather Becker ... [et al.]

Type Vis Mat
Call 616.855/Transd
Title Transdisciplinary team strategies [videorecording] : focusing on communication skills development
Auth Stat June Downing, Kathleen Stremel ; Educational Telecommunications Network ; Interactive Satellite Teleconference ; Teache

Type Vis Mat
Call 419/Coacti/5,6
Title A Coactive sign system for deaf-blind children [videorecording] : Lesson 5 : Daily routines : washing and bathing ; Mini lesson 5: form and speed in coactive signing ; Lesson 6 : Daily
Auth Stat directors, Paula Pitman, Sue Watkins ; SKI*HI Institute, Dept. of Communication Disorders, Utah State Universitu

Type Book
Call 419/Coacti SKI*
Title SKI*HI coactive tactile sign language video tape program : instruction booklet

Type Vis Mat
Call 419/Coacti/1,2
Title A Coactive sign system for deaf-blind children [videorecording] : Lesson 1 : Family members and interacting with family ; Mini lesson 1: How to approach and leave your child; importance

Auth Stat	directors, Paula Pittman, Sue Watkins ; SKI*HI Institute, Dept. of Communication Disorders, Utah State Universitu

Type	Vis Mat
Call	419/Coacti/7,8
Title	A Coactive sign system for deaf-blind children [videorecording]
Subtitle	Lesson 7 : Daily routines: play and sensory stimulation ; Mini lesson 7: Encouraging child to make signs on his own; re
Auth Stat	directors, Paula Pittman, Sue Watkins ; SKI*HI Institute, Dept. of Communication Disorders, Utah State Universitu

Type	Vis Mat
Call	419/Coacti/9,10
Title	A Coactive sign system for deaf-blind children [videorecording] : Lesson 9 : Action words in daily routines ; Mini lesson 9: Maximizing child's residual senses when using coactive signi
Auth Stat	directors, Paula Pittman, Sue Watkins ; SKI*HI Institute, Dept. of Communication Disorders, Utah State Universitu

Type	Vis Mat
Call	419/Coacti/11,12
Title	A Coactive sign system for deaf-blind children [videorecording] : Lesson 11 : Going places and visiting people ; Mini lesson 11: Conveying meanings and emotions in coactive signing ; L
Auth Stat	directors, Paula Pittman, Sue Watkins ; SKI*HI Institute, Dept. of Communication Disorders, Utah State Universitu

Type	Vis Mat
Call	419/Coacti/1-8
Title	A Coactive sign system for deaf-blind children [videorecording] : backup units 1-8
Auth Stat	directors, Paula Pittman, Sue Watkins ; SKI*HI Institute, Dept. of Communication Disorders, Utah State Universitu

Type	Vis Mat
Call	419/Coacti/17-20
Title	A Coactive sign system for deaf-blind children [videorecording] : backup units 17-20
Auth Stat	directors, Paula Pittman, Sue Watkins ; SKI*HI Institute, Dept. of Communication Disorders, Utah State Universitu

Type	Vis Mat
Call	419/Coacti/9-16
Title	A Coactive sign system for deaf-blind children [videorecording] : backup units 9-16
Auth Stat	directors, Paula Pittman, Sue Watkins ; SKI*HI Institute, Dept. of Communication Disorders, Utah State Universitu

Type	Vis Mat
Call	362.1/Regula Regu
Title	Regular lives [videorecording]
Auth Stat	a production of State of the Art, Inc. ; produced and directed by Tom Goodwin, Gerardine Wurzburg ; writer, Tom Goodwin

Type	Vis Mat
Call	616.855/Develo
Title	Developing communication skills through transdisciplinary team interventions [videorecording]
Auth Stat	June Downing, Kathleen Stremel ; Educational Telecommunications Network ; Interactive Satellite Teleconference ; Teache

Type	Vis Mat
Call	616.855/Develo
Title	Developing communication skills through transdisciplinary team interventions [videorecording]
Auth Stat	June Downing, Kathleen Stremel ; Educational Telecommunications Network ; Interactive Satellite Teleconference ; Teache

Type	Book
Call	362.404/Lazzar
Main	Lazzari, Andrea M
Title	The transition sourcebook : a practical guide for early intervention programs
Auth Stat	Andrea M. Lazzari ; illustrations drawn under contract by Cathie Lowmiller

Type	Vis Mat
Call	649.1/511/Heart
Title	Heart to heart [videorecording] : conversations with parents of blind children
Auth Stat	created by Nancy Chernus-Mansfield and Marilyn Horn ; written by Ron Mansfield ; produced by Bob Borgen

Type	Vis Mat
Call	616.855/Develo
Title	Developing tactile skills of students with deaf-blindness [videorecording] ; Talk into my hands
Auth Stat	produced by Michigan Services for Deaf-Blind Children and Youth ; LTS Productions ; Beverly Lang, producer

Type	Vis Mat
Call	616.855/Express
Title	Expressive communication [videorecording] : helping at school and home
Auth Stat	Deborah Chen

Type	Book
Call	616.836/Childr
Title	Children with cerebral palsy : a parents' guide
Auth Stat	edited by Elaine Geralis ; foreword by Tom Ritter

Type	Book
Call	618.92/Child
Title	Children with epilepsy : a parents guide

Type	Book
Call	649.15/Schwar
Main	Schwartz, Sue
Title	The language of toys : teaching communication skills to special-needs children : a guide for parents and teachers
Auth Stat	Sue Schwartz, Joan E. Heller Miller

Type	Book
Call	Lee,
Title	Lee, the rabbit with epilepsy

Type	Book
Call	A re
Title	A reader's guide

Type	Realia
Call	T28/PoPo
Title	PoPo the pocket monkey

Type	Realia
Call	SS17/Deep
Title	Deep heat adjustable back massager

Type	Realia
Call	SS18/Deep
Title	Deep heat back massager pad

Type	Realia
Call	SS19/Back
Title	Back massager with "infra-red" massager heat

Type	Realia
Call	SS20/Mini
Title	Mini massager

Type	Realia
Call	SW1/Leaf
Title	Leaf switch

Type	Realia
Call	SW2/Mercur
Title	Mercury switch

Type	Realia
Call	SW1/Toilet
Title	Toilet training switch

Type	Book
Call	371.9/Reid
Main	Reid, Dennis
Title	Providing choices and preferences for persons who have severe handicaps : practical procedures for good times
Auth Stat	Dennis H. Reid, Marsha B. Parsons and Carolyn W. Green

Type	Vis Mat
Call	616.855/Observ
Title	Observing and enhancing communication skills for individuals with multisensory impairments
Auth Stat	project directors, Victor Baldwin, Michael Bullis, Ron Thorkildsen ; project coordination, Penny H. Findlay ; instructi

Type	Book
Call	371.9/Smith
Main	Smith, Pamela
Title	Integrating related services into programs for students with severe and multiple handicaps
Auth Stat	Pamela D. Smith

Type	Book
Call	371.904/Integra
Title	Integrated programming : strategies, methods and monitoring of services for students with severe and multiple handicaps

Type	Book
Call	618.928/Hanna
Main	Hanna, Lynn M.
Title	Positioning and adaptive equipment

Auth Stat	Lynn M. Hanna
Type	Book
Call	616.855/DeFazi
Main	DeFazio, Jeannie Levin
Title	Programming for augmentative communication
Type	Book
Call	152.1/Young
Main	Young, Mary Helen
Title	Sensory integration programming
Auth Stat	Mary Helen Young
Type	Book
Call	616.855/Wilcox
Main	Wilcox, M. Jeanne
Title	Young children with disabilities : facilitating initial communication skills through partner programming
Auth Stat	M. Jeanne Wilcox, Juli Baumgarner, Susan Caswell
Type	Vis Mat
Call	152.15/Audit
Title	Auditory levels
Auth Stat	produced by the Ski*Hi Institute, Department of Communication Disorders, Utah State University ; direction, Sue Watkins
Type	Vis Mat
Call	618.928/Childr/1
Title	Children with motor impairments (tape 1)
Auth Stat	Ski*Hi Institute and INSITE Outreach
Type	Realia
Call	SS21/Gusty
Title	Gusty personal fan
Type	Realia
Call	T29/Batter
Title	Battery operated swirl art
Type	Realia
Call	SS22/Hots
Title	The Hots
Type	Realia
Call	T30/Viciou
Title	Vicious robo-dragon
Type	Realia
Call	T31/Toy
Title	Toy turtle
Type	Realia
Call	T32/Casio
Title	Casio PT-10
Type	Realia
Call	SW7/Contro
Title	Control unit

Type	Book
Call	616.855/Commun
Title	Communication programming for students with severe and multiple handicaps
Auth Stat	Pamela D. Smith and Jane O'Regan Kleinert, editors

Type	Book
Call	616.855/Resear
Title	Research on the communication development of young children with deaf-blindness
Auth Stat	edited by Michael Bullis

Type	Book
Call	616.855/Commun
Title	Communication development of young children with deaf-blindnessliterature review
Auth Stat	edited by Michael Bullis & Glen Fielding

Type	Book
Call	612.84/Jedros
Main	Jedrosz, Aleksander
Title	Eyes
Auth Stat	Aleksander Jedrosz ; illustrated by Andrew Farmer and Robina Green

Type	Book
Call	371.911/Everso
Main	Everson, Jane M
Title	Interagency collaboration for young adults with deaf-blindness : toward a common] transition goal
Auth Stat	written by Jane M. Everson, Patricia Rachal, Martha G. Michael

Type	Book
Call	362.41/Davenp
Main	Davenport, Sandra L. H.
Title	The vision/hearing loss presentation packet
Auth Stat	by Sandra L. H. Davenport

Type	Kit
Call	510/Focus
Title	FOCUS in mathematics : fundamental operations and concepts : underlying schema
Auth Stat	by Frank L. Franks ... [et al.]

Type	Book
Call	617.03/Werner Wern Disa
Main	Werner, David
Title	Disabled village children : a guide for community health workers, rehabilitation workers, and families
Auth Stat	by David Werner ; drawings by the author

Type	Realia
Call	OM2/Roll
Title	Roll

Type	Realia
Call	SS26/Sinkad
Title	Sinkadink : the kids' sink

Type	Realia
Call	T1/Call

Title Call bell

Type Realia
Call T2/Spinni
Title Spinning rainbow bells

Type Realia
Call T3/Light
Title Light fun wheel

Type Realia
Call T4/Musica
Title Musical telephone

Type Realia
Call T5/Sound
Title Sound tube rattle

Type Realia
Call T6/Puf
Title Puf-links

Type Realia
Call T7/Wind
Title Wind-up toy locomotive

Type Realia
Call T8/Sound
Title Sound tube toy

Type Book
Call 617.8/Flexer
Main Flexer, Carol
Title Guidelines for determining functional hearing in school-based settings
Auth Stat Carol Flexer, Kathleen Shelby, M. Jeanne Wilcox (editor)

Type Book
Call 612.84/Campbe
Main Campbell, Philippa H
Title Guidelines for determining functional use of vision in school-based settings
Auth Stat Philippa H. Campbell, Juli Baumgarner, M. Jeanne Wilcox (editor)

Type Realia
Call SS27/Dynast
Title Dynasty classics [personal fan]

Type Book
Call 371.904/MAPS
Title MAPS : a plan for including all children in schools

Type Book
Call 912/Impera
Main Imperatore, William
Title The braille world atlas
Auth Stat by William Imperatore, James Sanders

Type Book
Call 362.41/Direct

Title Directory of agencies and organizations serving individuals who are deaf-blind
Auth Stat compiled and published by Helen Keller National Center for Deaf-Blind Youths and Adults

Type Book
Call 362.41/084/Transi
Title Transition and individual futures planning : for people with deaf-blindness and developmental disabilities and their families
Auth Stat prepared by The Arc-King County and Common Ground

Type Vis Mat
Call 616.855/Gestur
Title Gestures : the missing link to language
Auth Stat script, Diane Pien, Julia McKibbin Klein ; producer/editor, Alfred Ross, Julia McKibbin Klein

Type Book
Call 618.92/Batsha
Main Batshaw, Mark L
Title Children with disabilities : a medical primer
Auth Stat by Mark L. Batshaw and Yvonne M. Perret

Type Realia
Call SS28/Little e
Title The Little room
Auth Stat idea, Lilli Nielsen

Type Book
Call 649.152/Childre
Title Children with mental retardation : a parent's guide
Auth Stat edited by Romayne Smith

Type Book
Call 612.313/Johnso
Main Johnson, Hilary
Title A practical approach to saliva control
Auth Stat by Hilary Johnson and Amanda Scott ; illustrations drawn under contract by Corwyn Zimbleman

Type Book
Call 362.4/186/Sauerb
Main Sauerburger, Dona,
Title Independence without sight or sound : suggestions for practitioners working with deaf-blind adults
Auth Stat Dona Sauerburger

Type Realia
Call SS30/Heat
Title Heat grid

Type Vis Mat
Call 362.41/Guidel
Title Guidelines for parent advisors : sample home visit

Type Vis Mat
Call 618.928/Childr/2
Title Children with motor impairments (tape 2)

Auth Stat	produced by the Ski*Hi Institute, Dept. of Communicative Disorders, Utah State University
Type	Vis Mat
Call	649.15/Helpin/V.1
Title	"Helping your child learn" series
Type	Vis Mat
Call	649.15/Helpin/V.2
Title	"Helping your child learn" series
Type	Vis Mat
Call	649.15/Helpin/V.3
Title	"Helping your child learn" series
Type	Book
Call	371.9/0460973/Restru
Title	Restructuring for caring and effective education : an administrative guide to creating heterogeneous schools
Auth Stat	edited by Richard A. Villa ... [et al.]
Type	Book
Call	371.9/0460973/Cooper
Title	Cooperative learning and strategies for inclusion : celebrating diversity in the classroom
Auth Stat	edited by JoAnne W. Putnam
Type	Book
Call	371.9/Rainfo Rain Coll
Main	Rainforth, Beverly,
Title	Collaborative teams for students with severe disabilities : integrating therapy and educational services
Auth Stat	by Beverly Rainforth, Jennifer York and Cathy Macdonaid ; with contributions by Christine Salisbury and Winnie Dunn
Type	Vis Mat
Call	649.151/Power
Title	Power of the heart
Auth Stat	directed by Dale Rubin and Martha Boethel ; producer, Martha Boethel ; script by Martha Boethel
Type	Realia
Call	SS31/Kickin
Title	Kicking board
Type	Realia
Call	S1/Bath
Title	Bath chair
Type	Ssd rec
Call	152.4/Grievi
Title	Grieving workshop
Type	Book
Call	615.822/Schnei
Main	Schneider, Vimala
Title	Infant massage : a handbook for loving parents
Auth Stat	Vimala Schneider McClure

Type	Vis Mat
Call	419/Commun
Title	Communicating with children who are deaf-blind : signals and clues
Auth Stat	SKI*HI Institute ; written, directed and produced by Paula Pittman ... [et al.]

Type	Book
Call	362.41/Resour
Title	A Resource manual for understanding and interacting with infants, toddlers, and preschool age children with deaf-blindn
Auth Stat	editor, Linda Alsop

Type	Book
Call	371.912/Terry
Main	Terry, Barbara Graham
Title	SKI*HI programming for children with chronic middle ear disease
Auth Stat	Barbara Graham Terry

Type	Book
Call	362.41/Sall
Main	Sall, Nancy
Title	Technological resources for students with deaf-blindness and severe disabilities
Auth Stat	Nancy Sall, Harvey H. Mar

Type	Book
Call	362.41/Proceed
Title	Proceedings of the National Symposium on Children and Youth Who Are Deaf-Blind
Auth Stat	John W. Reiman, Pattie A. Johnson, editors

Type	Book
Call	649.122/Hussey
Main	Hussey, Brenda
Title	Understanding my signals
Auth Stat	Brenda Hussey

Type	Book
Call	362.41/Model/V.1
Title	A Model of home intervention for infant, toddler, and preschool aged multihandicapped sensory impaired children : the INSITE model
Auth Stat	editor, Susan Watkins

Type	Book
Call	362.41/Model/V.2
Title	A Model of home intervention for infant, toddler, and preschool aged multihandicapped sensory impaired children : the INSITE model
Auth Stat	editor, Susan Watkins

Type	Book
Call	371.911/Perkin/V.1
Title	Perkins activity and resource guide : a handbook for teachers and parents of students with visual and multiple disabilities
Auth Stat	principal authors: Kathy Heydt, Mary Jane Clark, Charlotte Cushman, Susan Edwards, Monica Allon.

Type	Book
Call	371.911/Perkin/V.2
Title	Perkins activity and resource guide : a handbook for teachers and parents of students with visual and multiple disabilities
Auth Stat	principal authors: Kathy Heydt, Mary Jane Clark, Charlotte Cushman, Susan Edwards,

Monica Allon.

Type	Book
Call	362.1/968/Colema
Main	Coleman, Jeanine G
Title	The early intervention dictionary : a multidisciplinary guide to terminology
Auth Stat	Jeanine G. Coleman

Type	Book
Call	371.2/00973/Glasse
Main	Glasser, William,
Title	The quality school : managing students without coercion
Auth Stat	William Glasser

Type	Book
Call	371.9/046/Pearpo
Main	Pearpoint, Jack,
Title	The inclusion papers : strategies to make inclusion work : a collection of articles from the Centre
Auth Stat	by Jack Pearpoint, Marsha Forest and Judith Snow

Type	Vis Mat
Call	371.904/Concept
Title	The Concept and the practice
Auth Stat	Indiana University Production ; executive producer, Leonard C. Burrello ; producers, Leonard C. Burello, John Burrello,

Type	Vis Mat
Call	612.84/Vision
Title	Vision screening project

Type	Vis Mat
Call	371.904/MAPS
Title	MAPS : a plan for including all children in schools
Auth Stat	presented by the Kansas State Dept. of Education, Services for Deaf-Blind Children and Youth Project ; produced by Inno

Type	Vis Mat
Call	371.904/Collab
Title	Collaborative teaming for inclusion oriented schools
Auth Stat	Kansas State Dept. of Education, Special Education Outcomes Team ; Facilitating The Least Restrictive Environment for S

Type	Vis Mat
Call	362.41/Young
Title	Young, deaf and visually impaired : an introductory film by and of deaf Swedish young people who suffer from RP (retinitis pigmentosa)
Auth Stat	manus, Susanne Stjarnlof, Bjorn Sandberg ; oversttning fran svenska till techensprak, Susanne Stjarnlof ; kamera, redig

Type	Book
Call	155.413/Rogers
Main	Rogers, Sally J
Title	Developmental programming for infants and young children, 1, assessment and application
Auth Stat	by Sally J. Rogers and Diane B. D'Eugenio

Type	Book

Call 371.26/Guide
Title A Guide for the vocational assessment and development of multiply handicapped youth
Auth Stat project director, Stephen W. Lowery

Type Book
Call 362.41/ICAN
Title I.C.A.N. : a functional skills assessment for the Deaf-Blind
Auth Stat developed by the Perkins School for the Blind, Deaf-Blind Department, Total Life Planning Grant ; Janet Wessell, direct

Type Vis Mat
Call 649.1/511/Lets
Title Let's eat : feeding skills for children with visual impairments
Auth Stat written, produced and directed by Chris Richter, Chris Starr ; S.C.O.R.E. Media

Type Vis Mat
Call 616.855/Commun/1,2,3,4
Title Communicating with children who are deaf-blind : signals and cues : Laying the foundation for using signals and cues in daily activities and routines
Auth Stat produced by SKI*HI Institute ; written, directed and produced by Paula Pittman ... [et al.]

Type Vis Mat
Call 616.855/Commun/5,6
Title Communicating with children who are deaf-blind : signals and cues : Laying the foundation for using signals and cues in daily activities and routines
Auth Stat produced by SKI*HI Institute ; written, directed and produced by Paula Pittman ... [et al.]

Type Vis Mat
Call 616.855/Commun/7,8
Title Communicating with children who are deaf-blind : signals and cues : Laying the foundation for using signals and cues in daily activities and routines
Auth Stat produced by SKI*HI Institute ; written, directed and produced by Paula Pittman ... [et al.]

Type Vis Mat
Call 616.855/Commun/9,10
Title Communicating with children who are deaf-blind : signals and cues : Laying the foundation for using signals and cues in daily activities and routines
Auth Stat produced by SKI*HI Institute ; written, directed and produced by Paula Pittman ... [et al.]

Type Vis Mat
Call 616.855/Commun/11,12
Title Communicating with children who are deaf-blind : signals and cues : Laying the foundation for using signals and cues in daily activities and routines
Auth Stat produced by SKI*HI Institute ; written, directed and produced by Paula Pittman ... [et al.]

Type Book
Call 371.9/046/Lesson
Title Lessons for inclusion : including everyone, liking myself, making & keeping friends, cooperating with others
Auth Stat Terri Vandercook ... [et al.]

Type Vis Mat
Call 617.103/Early
Title The Early communication process using microswitch technology
Auth Stat Charity Rowland, Philip Schweigert ; Communication Skill Builders ; Oregon Research Institute

Type Vis Mat

Call 371.904/Miller
Title Miller's MAP
Auth Stat with Marsha Forest, Jack Pearpoint, Bob Reagston ; executive producers, Expectations Unlimited, Inclusion Press ; direc

Type Book
Call 616.855/Connar
Main Connard, Patricia A
Title P.A.I.P. : the preverbal assessment-intervention profile : manual
Auth Stat by Patricia A. Connard

Type Book
Call 616.855/NADBRH
Title The "NADBRH" schedule of communication development in deaf/blind children

Type Book
Call 150.287/Wiscon
Title Wisconsin behavior rating scale
Auth Stat authored by Agnes Song ... [et al.]

Type Book
Call 371.911/Inclus
Title Inclusive instructional design : facilitating informed and active learning for individuals who are deaf-blind in inclusive schools
Auth Stat Katheleen Gee ... [et al.]

Type Book
Call Thomps
Main Thompson, Mary
Title My brother, Matthew
Auth Stat Mary Thompson

Type Realia
Call OFFICE/Three
Title Three-panel display screen

Type Book
Call 362.41/084/SCIP
Title SCIP : school community innovative practices

Type Book
Call 362.41/0924/Stenqu
Main Stenquist, Gertrude
Title The story of Leonard Dowdy : deaf-blindness acquired in infancy
Auth Stat by Gertrude Stenquist

Type Book
Call 372.11/023/Paley
Main Paley, Vivian Gussin,
Title You can't say you can't play
Auth Stat Vivian Gussin Paley

Type Book
Call 370.19/0973/Siccon
Main Siccone, Frank
Title Celebrating diversity : building self-esteem in today's multicultural classrooms
Auth Stat Frank Siccone

Type	Book
Call	371.9/Craig
Main	Craig, Susan
Title	Integrated therapies : speech and language, physical, occupational
Auth Stat	authors, Susan Craig, Ann G. Haggart

Type	Book
Call	371.9/0460973/Giangr
Main	Giangreco, Michael F
Title	Choosing options and accommodations for children (COACH) : a guide to planning inclusive education
Auth Stat	by Michael F. Giangrieco, Chigee J. Cloninger, and Virginia Salce Iverson

Type	Book
Call	371.911/First
Title	First steps : a handbook for teaching young children who are visually impaired

Type	Realia
Call	C13/Voice
Title	VoicePal

Type	Book
Call	371.11/0973/Welcom
Title	Welcoming students who are deaf-blind into typical classrooms : facilitating school participation, learning, and friendships
Auth Stat	edited by Norris G. Haring and Lyle T. Romer

Type	Book
Call	371.911/Transi
Title	Transition services for youths who are deaf-blind : a "best practices" guide for educators
Auth Stat	Jane M. Everson, editor

Type	Book
Call	371.911/Buildi Buil
Title	Building effective transition strategies for individuals with deaf-blindness
Auth Stat	Cathy Mouchka ... [et al.]

Type	Book
Call	331.591/0973/Assess
Title	An assessment instrument for families : evaluating employment programs for individuals with deaf-blindness
Auth Stat	developed by Helen Keller National Center - Technical Assistance Center

Type	Book
Call	362.41/084/Mount
Main	Mount, Beth
Title	It's never too early, it's never too late : a booklet about personal futures planning : for persons with developmental disabilities, their families and friends, ca
Auth Stat	written by Beth Mount and Kay Zwernik

Type	Book
Call	616.31/Klein
Main	Klein, Marsha Dunn
Title	Feeding and nutrition for the child with special needs : handouts for parents
Auth Stat	Marsha Dunn Klein, Tracy A. Delaney ; edited by Christine Ravashiere Medvescek ; illustrations drawn under contract by

Type	Vis Mat

Call 371.904/School
Title Schools are for all kids : full integration
Auth Stat producers, Dotty Kelly, Lori Goetz ; California Research Institute, San Francisco State University

Type Vis Mat
Call 371.394/Gettin
Title Getting together ... peer tutoring
Auth Stat executive producers, California Research Institute, Frederick Burk Foundation, Inc., Dept. of Special Education, San Fr

Type Vis Mat
Call 790.196/Integr
Title Integrated play groups
Auth Stat created and produced by Pamela Wolfberg ; Integrated Play Group Productions, Inc.

Type Vis Mat
Call 362.41/Deaf
Title Deafblindness : a unique disability ; Independence with intervention ; Living in the community
Auth Stat Canadian Deafblind and Rubella Association ; director, Chuck Lapp ; producer, Karen Thomas ; writer, Carol Millett

Type Vis Mat
Call 371.911/You
Title You & me
Auth Stat Idaho Deaf Blind Project, Center on Developmental Disabilities, University of Idaho

Type Book
Call 371.904/60973/Toward
Title Toward inclusive classrooms

Type Book
Call 362.41/0835/Suppor
Title Supporting young adults who are deaf-blind in their communities : a transition planning guide for service providers, families and friends
Auth Stat edited by Jame M. Everson

Type Realia
Call SS37/Little
Title The Little room

Type Book
Call 346.7/3052/Planni
Title Planning for the future : providing a meaningful life for a child with a disability after your death
Auth Stat L. Mark Russell ... [et al.]

Type Book
Call 371.911/Select
Title Selected readings on the preparation of personnel for the education of students who are deaf-blind
Auth Stat Norma Tedder ... [et al.]

Type Book
Call 155.413/Morgan
Main Morgan, Elizabeth

Title	Assessment of developmental skills for young multihandicapped sensory impaired children : an instruction manual for the INSITE developmental checklist
Auth Stat	Elizabeth Morgan, Sue Watkins

Type	Book
Call	362.41/Parent
Title	Parent advising : personal experiences and reactions

Type	Book
Call	371.911/Hand
Title	Hand in hand : essentials of communication and orientation and mobility for your students who are deaf-blind : a trainer's manual
Auth Stat	Jeanne Glidden Prickett ... [et al.]

Type	Book
Call	371.911/Hand
Title	Hand in hand : selected reprints and annotated bibliography on working with students who are deaf-blind
Auth Stat	Kathleen Mary Huebner ... [et al.]

Type	Book
Call	371.911/Hand/V.1
Title	Hand in hand : essentials of communication and orientation and mobility for your students who are deaf-blind : Volume I: Units 1, 2,
Auth Stat	Kathleen Mary Huebner ... [et al.]

Type	Book
Call	371.911/Hand/V.2
Title	Hand in hand : essentials of communication and orientation and mobility for your students who are deaf-blind : Volume II: appendixes,
Auth Stat	Kathleen Mary Huebner ... [et al.]

Type	Vis Mat
Call	371.911/Hand
Title	Hand in hand : it can be done
Auth Stat	American Foundation for the Blind ; executive producer, Dick Ridgeway ; producer, Janice Reynolds ; director/editor, Ki

Type	Kit
Call	617.8/Hear Hear
Title	Hear-kit

Type	Book
Call	362.33/Lobato
Main	Lobato, Debra J.,
Title	Brothers, sisters, and special needs : information and activities for helping young siblings of children with chronic illnesses and developmental disabilities
Auth Stat	by Debra J. Lobato

Type	Book
Call	371.9/0973/Cutler
Main	Cutler, Barbary Coyne
Title	You, your child, and "special" education : a guide to making the system work
Auth Stat	by Barbara Coyne Cutler

Type	Book
Call	790.196/0973/Making
Title	Making school and community recreation fun for everyone : places and ways to integrate
Auth Stat	edited by M. Sherril Moon

Type	Book
Call	362.404/3083/Meyer
Main	Meyer, Donald J
Title	Sibshops : workshops for siblings of children with special needs
Auth Stat	by Donald J. Meyer and Patricia F. Vadasy

Type	Book
Call	362.1/9892/Rosenf
Main	Rosenfeld, Lynn Robinson,
Title	Your child and health care : a "dollars & sense" guide for families with special needs
Auth Stat	by Lynn Robinson Rosenfeld

Type	Book
Call	790.196/Lifelo
Title	Lifelong leisure skills and lifestyles for persons with developmental disabilities
Auth Stat	by Stuart J. Schleien ... [et al.]

Type	Book
Call	649.152/Uncomm
Title	Uncommon fathers : reflections on raising a child with a disability
Auth Stat	edited by Donald J. Meyer

Type	Book
Call	371.9/0973/Rosenb
Main	Rosenberg, Michael S.
Title	The special education sourcebook : a teacher's guide to programs, materials, and information sources
Auth Stat	Michael S. Rosenberg and Irene Edmond-Rosenberg

Type	Realia
Call	CO1/Hard Hard
Title	Hard drivers 10 : amplified computer speakers

Type	Realia
Call	H1/Phonic Phon
Title	Phonic Ear Easy Listener personal FM system

Type	Realia
Call	CO2/Intell Inte
Title	IntelliKeys with four cables

Type	Book
Call	371.911/Chen
Main	Chen, Deborah
Title	Starting points : instructional practices for young children whose multiple disabilities include visual impairment
Auth Stat	by Deborah Chan and Jamie Dote-Kwan

Type	Book
Call	649.151/From
Title	From the heart : on being the mother of a child with special needs
Auth Stat	authors, Patricia Bowman (Pat) ... [et al.] ; editors, Jayne D. B. Marsh, Carol Boggis

Type	Book
Call	371.9/114/Simon "Sim
Title	"Simon says" is not the only game
Auth Stat	compiled by Bernadette Leary and Margaret von Schneden

Type	Realia
Call	C1/BIGmac
Title	BIGmack : single-message voice output communication aid

Type	Vis Mat
Call	302.222/Tangib
Title	Tangible symbol systems for individuals with multi-sensory impairments
Auth Stat	Charity Rowland, Philip Schweigert ; photography by Bergman Photographic Service

Type	Book
Call	618.92/097533/Care
Title	The Care of children with long-term tracheostomies
Auth Stat	Ken M. Bleile, editor

Type	Vis Mat
Call	615.822/Pediat
Title	Pediatric massage for the child with special needs
Auth Stat	with Kathy Fleming Drehobl and Mary Gengler Fuhr ; produced by Therapy Skill Builders ; videotape, editing, and product

Type	Vis Mat
Call	616.855/Partne
Title	Partners in language
Auth Stat	producer, Charlotte Cote ; director, Debbi Honorof ; writer, Deborah Harlin ; Helen Keller National Center

Type	Vis Mat
Call	616.855/Deaf
Title	Deaf-blind : overview and introduction : communication & community
Auth Stat	director, Dennis Cokely ; Sign Media, Inc.

Type	Vis Mat
Call	616.855/Deaf
Title	Deaf-blind : getting involved : a conversation : communication & community
Auth Stat	director, Dennis Cokely ; Sign Media, Inc.

Type	Vis Mat
Call	649.122/Introd
Title	An Introduction to the NICU
Auth Stat	produced by the Newborn Transition Project of the Kansas Early Childhood Research Institute, the University of Kansas ;

Type	Vis Mat
Call	649.122/Caring
Title	Caring for your NICU baby
Auth Stat	produced by the Newborn Transition Project of the Kansas Early Childhood Research Institute, the University of Kansas ;

Appendix B

Satisfaction Surveys

Alaska Services for Children and Youth with Dual Sensory Impairments

Consumer Satisfaction Rating Form by School Districts, Infant Learning Programs, Agencies

The following information will provide the Dual Sensory Impairment Program (DSI) with information concerning your satisfaction of the technical assistance provided to you during the 1994-95 year.

*Please mark a **check** next to the services you have received from the DSI Program. If an item **does not apply**, **leave blank**.*

__5__ Workshop or Inservice Training

__13__ Student Observations

__4__ Teleconferences

___ Video Consultations

__2__ Home Visits

__13__ On-site Visits

__8__ Library/Equipment Loan

__9__ Resource or Instructional Material

__10__ Phone Contact

__5__ Program Development

__7__ IEP/CST/IFSP/MAPS Meeting(s) or Assistance

__4__ Identifying Instructional Strategies

__6__ Networking Opportunities

__11__ "Keeping In Touch" Newsletter

__7__ Assistance with attending conferences, workshops

__4__ Assessments

__1__ Other (Describe)

*Please **circle** one choice for each item. If item **does not apply** to your situation or relationship to the specialist or activity, **circle N/A**.*

	Strongly Disagree				Strongly Agree
On-site Visits					
A. The contact by the education specialist prior to each on-site visit was helpful to establish the purpose of the visit.	1	2	3(4)	4(7)	N/A(4)
B. The individual assistance was helpful in meeting identified needs.	1	2(1)	3(4)	4(9)	N/A
C. Follow-up activities/requests were timely and useful.	1	2	3(4)	4(8)	N/A(2)
D. The Student Service Report received after each visit was:					
• Clear, concise, and easy to follow	1	2	3(1)	4(8)	N/A(4)
• Received within an appropriate time span after each visit.	1	2	3(2)	4(7)	N/A(4)
• Helpful	1	2	3(2)	4(7)	N/A(4)

E. The Education Specialist:

• was sensitive to student, family and district needs	1	2(2)	3(1)	4(11)	N/A
• was knowledgeable and informative	1(1)	2	3(1)	4(12)	N/A
• was well-prepared for the visit	1(1)	2	3(2)	4(11)	N/A
• maintained useful contact between on-site visits	1	2	3(2)	4(9)	N/A(2)
• was available for contact between visits	1(1)	2	3(2)	4(11)	N/A
• was an effective resource	1	2	3(2)	4(11)	N/A

***Optional*: Additional Comments (follow on last page)**

1. What was most beneficial about the on-site visits?

_____

_____

2. What, if anything, would you prefer to be different (use of time, people, etc.)?

_____

_____

The program as a source of information

A. Has telephone communication with the staff been:

• timely	1	2	3(1)	4(8)	N/A(3)
• useful	1	2	3(1)	4(9)	N/A(2)
• responsive	1	2	3(1)	4(9)	N/A(2)
B. The newsletter, *Keeping In Touch*, provided useful information	1	2	3(4)	4(7)	N/A(1)
C. The mailings have been useful	1	2	3(4)	4(7)	N/A(1)
D. Professional materials borrowed from the program were useful.	1	2	3(3)	4(5)	N/A(4)

***Optional*: Additional Comments (follow on last page)**

1. What was most beneficial?

_____

_____

2. What, if anything, would you prefer to be different (use of time, people, etc.)?

_____

_____

Workshops and Inservice Presentations

Workshops and inservices I attended:

A. increased awareness and/or skills.	1	2	3(2)	4(4)	N/A(5)
B. resulted in useful information.	1	2	3(1)	4(5)	N/A(4)
C. addressed the needs of staff, family, or student	1	2	3(3)	4(3)	N/A(4)

***Optional*: Additional Comments (follow on last page)**

1. What was most beneficial about the workshop or inservice?

_____

_____

2. What, if anything, would you prefer to be different (use of time, people, etc.)?

_____

_____

Future Needs

Training and technical assistance would best be accomplished through:

12	site visits by specialist	8	networking with other service providers
9	attending conferences, wórkshops	5	district workshops/inservices
7	visiting other sites	___	interactive video-conferencing
11	ongoing telephone contact	3	videotape reviews
6	mailings	3	retreat
4	statewide teleconferences addressing specific topics	___	other?

Person completing this form is:

1	administration	5	special education teacher
1	district deaf-blind coordinator	1	regular education teacher
1	related service staff	1	teaching assistant
3	other?		

Are there other comments/suggestions you would like to make?

_____

_____

_____

Thank you for completing this form.
Please return it by June 1 in the enclosed envelope.

5/95

Alaska Services for Children and Youth with Dual Sensory Impairments

Parent Questionnaire

Dear Parents:

During 1994-1995 services were available to you, your child and your child's school program through the Dual Sensory Impairment Program (DSI). We would appreciate your feedback about any DSI services received so that we know what has and has not been helpful. Please return this evaluation at your earliest convenience. Thank you.

1. What services have been provided by the DSI program during 1994-95?

   Jenae has had the blind-deaf teacher come to her school weekly.
   Use of Tactaid for my sone who is deaf/blind.
   Very helpful information
   Visits from Sara Garr
   School visits
   Sent me some information.
   1 school visit
   Really I'm not certain, Sara.

	Yes	I Think So	Don't Know	I Don't Think So	No	Comments
2. Do you understand the services provided by the DSI program?	5		1			
3. Have the services been helpful?	4	1				

	Very Helpful	Somewhat Helpful	Not Helpful	Does Not Apply	Comments
4. Please comment about any services received in the following areas:					Pamphlets, phone calls, letters.
a. information received regarding dual-sensory impairments	3	1	1		
b. information about local, state, national resources	2	3			
c. assessment or evaluation information	3	1		1	
d. home and/or school visits and consultations	3	1		1	It was nice for them to see my sons progress and get new ideas.
e. assistance with transition planning	1	1		3	
f. assistance in obtaining and interpreting medical reports	1		1	3	Sara was very helpful when my son was in the hospital, we don't always know what to ask, & she really helped us.
g. assistance in child's home or school program	3	1		1	
h. support to attend meetings, conferences, etc.	3			2	Lots of information and we enjoy the family stories. re: Pathways
i. *Keeping In Touch* newsletter	3	1	1		
j. Other services?	2	1	1		

Additional Comments

	Yes	Sort Of	No	Does Not Apply	Comments
5. Please comment regarding services provided by the DSI specialist:					Always listens to your ideas & concerns.
a. sensitive to you and your child's needs	4			1	
b. was knowledgeable and informative	3	1		1	Always able to direct us to what we needed.
c. was available and accessible to you	3	1		1	Always
d. maintained contact	3	1		1	Kept contact through phone calls & letters.
e. was an effective resource	3	1	1		Very much so.

Additional Comments:

6. What were the most helpful aspects of the DSI program?

Conferences
School Visits
Keeping in contact through phone calls
Sharing new information
None for us.
In the past this program has been wonderful. We had so many other concerns this year I don't think I had much contact with DSI.
Helping Jeff's teachers learn to adapt materials

7. How might we improve our services?

Can't really improve the best!
Doesn't appear we need your services?
Have the funding to have you work with him hands on in the class several days so the teachers will have good ideas of what to do.

8. Are there areas that you would like more information or assistance?

Everything & everyone has always been most helpful.
No.

_____ _____
Date *Name (optional)*

Thank you for taking the time to complete this questionnaire. Please return in the enclosed envelope. *jf:7/95*

Alaska Services for Children and Youth with Dual Sensory Impairments

Parent Questionnaire

New Referral

Dear Parents:

During 1994-1995 your child was referred to the Dual Sensory Impairment Program (DSI). We would appreciate your feedback about the services received so that we know what has and has not been helpful. Please return this evaluation at your earliest convenience. Thank you.

1. How did you learn about the DSI program?

   When my son was evaluated for the preschool special education program, he was determined eligible for DSI services.

	Yes	I Think So	Don't Know	I Don't Think So	No	Comments
2. Did you receive a phone call or information about DSI services within a month after your child was referred to the DSI program?	1				1	
3. Do you understand the services provided by the DSI program?	1				1	
4. Have the services been helpful?	1			1		

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	Very Helpful	Somewhat Helpful	Not Helpful	Does Not Apply	Comments
5. Please comment about any services received in the following areas:					
a. information received regarding dual-sensory impairments	2				Especially the newsletter!
b. information about local, state, national resources	1	1			Father's group was helpful.
c. assessment or evaluation information		1	1		
d. home and/or school visits and consultations	1			1	
e. assistance with transition planning				2	
f. assistance in obtaining and interpreting medical reports				2	
g. assistance in child's home or school program	1			1	I really appreciate the coordination of services between Sarah & the school district
h. support to attend meetings, conferences, etc.	2				
i. *Keeping In Touch* newsletter	1			1	
j. Other services?	1				Looking forward to family camp.

Additonal Comments

	Yes	Sort Of	No	Does Not Apply	Comments
6. Please comment regarding services provided by the DSI specialist:					Sarah listens well and offers quiet support. She is great at being helpful in letting me know what services and supports are available to me without being pushy or making me feel like she knows best what I need. I really appreciate this quality of hers. Having a child with severe disabilities is diffucult enough without having to worry about services. Sarah has been terrific throughout. Thanks!
a. sensitive to you and your child's needs	1	1			
b. was knowledgeable and informative	1		1		
c. was available and accessible to you	1		1		
d. maintained contact	1			1	
e. was an effective resource	1			1	

Additional Comments:

7. What were the most helpful aspects of the DSI program?

   The coordination between the schools and SESA and the newsletter.
   I'm also really looking forward to tamily camp. I also appreciate the lending library.

8. How might we improve our services?

   Give me more information how to help.

9. Are there areas that you would like more information or assistance?

_____ _____
Date *Name (optional)*

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Thank you for taking the time to complete this questionnaire. Please return in the enclosed envelope.

jf:7/95

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Appendix C

Sample of Products Developed

Keeping In Touch

An Alaskan newsletter for families, friends, and educators involved with infants, children and youth who have dual-sensory impairments

Spring 1995

Spring Cleaning

by Sara J. Gaar, Ed.D., Supervisor

Spring is beginning to show its colors and with it comes new beginnings and new directions. It's also time to spring clean. Or in the case of the DSI (Dual Sensory Impairment) Program, it is when we begin filing away all of this year's completed projects and begin planning for next year.

As we pack away the project files it is clear how busy the DSI Program has been this year. Some of our key activities, besides the ongoing site visits to districts serving learners with deaf-blindness, included our involvement with the Alaska Statewide Special Education Conference. Two educational teams from Alaska provided valuable and practical workshops sharing their experiences including students with deaf-blindness. A special thanks to Mary Aronson-Toland, Bill Jacobsen, Leslie Keaton, and Donna McKinley for their excellent presentations! In addition to our instate expertise, Maurice Belote from California Deaf-Blind Services provided a very informative two-day workshop on transition through the ages with learners who are deaf-blind.

The Alaska Usher and Vision Screening Project file will remain an active one in the upcoming year. To date, there have been two teleconferences with Dr. Sandra Davenport concerning our statewide screening efforts. She reports that Alaska's rural screening model is unique and a lead model in the country!

As we spring forward into planning for the new year, we do so with some hesitation and reservation. To date, we have not heard whether we, or any of the other state deaf-blind projects, will be federally funded. Tom Hehir and Judith Heumann of the Office of Special Education and Rehabilitation Services (OSERS) have received letters from all over the country expressing the continued need for state deaf-blind resource centers, such as the DSI Program, and national technical assistance projects, such as TRACES, Helen Keller/TAC, and Deaf-Blind Link. Yet, the Administration has recommended zero funding for services to deaf-blind. For a thorough update on the status of IDEA and its relationship to deaf-blind services, please refer to Joseph McNulty's article, Legal Briefs: What's the big "IDEA?" (page 4).

The topic of this newsletter is families, in particular siblings. As I meet with families, I am constantly reminded about the impact and interdependency each family member has on each other. Infant and early childhood programs typically are provided in homes and tend to be family focused. Individual family service plans are used in early childhood programs. As children get older and enter school, the focus of education shifts away from the family and to the individual child with special needs. Although family involvement is considered critical in educational planning and implementation, we as educators of older students tend to not be involved with families to the same degree as in the early years. Yet, the family and each family member continue to directly affect each other throughout life.

We would like to dedicate this newsletter issue to families and, in particular, to the brothers and sisters of children with deaf-blindness.

Have a wonderful summer and happy spring cleaning!

I know that daisies and pansies come from seeds which have been put in the ground; but children do not grow out of the ground. I am sure. I have never seen a plant child...

-Helen Keller

Sibling Concerns

by Donald J. Meyer

Given that most brothers and sisters harbor a wide range of feelings toward their siblings, it is not at all unusual to learn that siblings of people with special needs also experience ambivalent feelings about their brothers and sisters. After all, a relationship in which one sibling has a disability or illness is still a sibling relationship. Adding a special need to the equation appears to enhance the inherent ambivalence.

It is difficult to make generalizations about siblings who have brothers and sisters with special needs, because this is only one aspect of their lives. Disabilities and illnesses affect people from all walks of life, and siblings will experience these conditions in innumerable ways. However, in listening to brothers and sisters, we hear recurring themes, despite the diverse backgrounds of these siblings. No one brother or sister will experience all of the concerns discussed below, but all will share some.

Over identification:

Over identification occurs when a sibling wonders whether he or she shares—or will share—a sibling's problem...The risk of over identification is one of the many reasons that brothers and sisters need accurate information about their siblings' disabilities and illnesses. Information that may be obvious to adults may not be to children. For instance, younger children need to know that they cannot "catch" their siblings' disability.

Embarrassment:

A sibling with a disability or illness can be a source of embarrassment for typically-developing brothers and sisters.

De eloping strategies to spare a typically-developing child embarrassment first requires analyzing the cause of the embarrassment. Is it something that can be changed, such as an age-inappropriate bib on a sibling who drools, or a behavior, such as singing during the sermon at church, that could be changed through a carefully considered behavior program? If changeable, then the family can work toward decreasing the sibling's embarrassment and improving the life of the person with special needs at the same time.

However, it is equally likely that the source of embarrassment is something about which little can be done. In these instances, there are two strategies parents may wish to consider. First, they should remember that most children go through stages when they are easily embarrassed, and these experiences may be unavoidable.

Early adolescents have a particularly strong need to conform. It can make a teenager miserable to be seen with her parents, much less with a sister who looks and acts differently. During this time of raging conformity, the best strategy may be to give the typically-developing child "space," psychological and otherwise. Given permission to walk on the other side of the shopping mall or attend a different church service, most siblings will eventually re-integrate their brother or sister.

A second strategy is to acknowledge the embarrassment. Denying siblings "permission" to be embarrassed by their sibling (as in "He's your brother; you shouldn't be embarrassed by him!") is more likely to invoke guilty feelings than to reduce embarrassment. It also will send a message that children cannot bring their concerns to their parents. Acknowledging that a sibling with special needs is sometimes difficult to live with not only reflects reality (after all, what sibling—special needs or not—is always easy to live with?), but it also sends a message that brothers and sisters can feel free to talk about their feelings with their parents.

Luckily, for most siblings, embarrassment is transitory. Most brothers and sisters have a remarkable ability to re-frame difficult situations in a more positive light.

Guilt:

Siblings of individuals with special needs are far more likely to experience guilt than siblings of individuals without special needs. Brothers and sisters may feel they caused their siblings' disability; they may experience survivor's guilt; they may feel guilty about their own abilities or about harboring less-than-charitable feelings about their siblings.

Isolation, Loneliness and Loss:

A sibling's disability or illness can cause brothers and sisters to experience various feelings of loss and isolation.

Especially if there are only two children in the family, typically-developing siblings may miss having a brother or sister with whom they can seek advice, or share their thoughts, hopes and dreams. They

Sibling Concerns (continued)
may also long for the rough-but-loving relationship many siblings share.

When parents are consumed with a child's disability or illness, typically-developing brothers and sisters can feel neglected and isolated from their parents. These feelings are especially keen during times of stress for the family, such as diagnoses or hospitalizations.

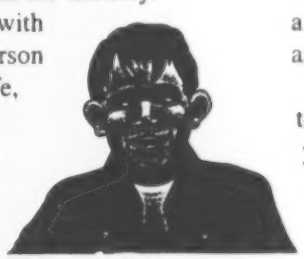
Of course, when a child is facing a health or developmental crisis, it may be impossible for parents to meet all their children's needs for emotional support. During trying times, many families enlist the support of a favorite relative or adult friend who provides the healthy child with time, attention, and an "open ear."

From Exceptional Parent, October 1994. Donald J. Meyer is the Director of the Sibling Support Project, Children's Hospital and Medical Center, Seattle, Washington. Don is the younger brother of two siblings who have epilepsy. He is married and the father of four children.

My Brother

By Audra Nabinger, Age 12

My brother is handicapped as you may know.
He really is not hard to be around.
The most popular question asked is "How do you communicate with him?"
Actually, sometimes he uses limited sign language.
Most of the time you just know.
It goes with the territory.
When you live with a handicapped person all of your life,
you just learn to read the person you're with.
All in all, my brother is a very regular person with regular feelings.
He just is unable to see, hear, and talk.
If you were to ask me "What is it like to have a handicapped brother?",
I'd probably say "What is it like to have a normal brother?"



SESA Library Resources on Inclusive Education

If you've been looking for books, videos or other resources about educating students with deaf-blindness or other intensive needs in regular classes, look no further. *SESA Library Resources on Inclusive Education* is a guide to books, videos and other resources available through the SESA library that support students with deaf-blindness or other intensive needs in regular classes. The resource guide is divided into six sections:

General Inclusion
Inclusion of students who are deaf-blind
Inclusion of students who are blind/visually impaired
Inclusion of students who are deaf or hard-of-hearing
Collaborative teaching and cooperative learning
Social skills and behavioral supports

Publications included in the guide provide information on successful strategies for inclusive education, adaptations for sensory impairments, examples of teachers talking about their experiences, examples of students in inclusive education environments, ideas for cooperative learning activities and adult collaboration, revised assessment techniques, and other relevant topics.

SESA Library Resources on Inclusive Education was compiled to assist educators, parents and others to access resources that are available to support educating students with deaf-blindness and other intensive needs together with peers without disabilities. As educators in the 1990's it is the responsibility of each of us to improve our ability to educate children with special needs in heterogeneous educational settings. Resources from the SESA library can be one support to help families and educators meet the inclusion challenge. For more information contact Fran Maiuri or Ann Freitag.

Cindy Davis has assumed the position of president of the Alaska National Association of Parents of Blind & Visually Impaired (AK NAPVI) since Marge Mochak has resigned. Cindy lives in the Anchorage area and has a 10 year old son who is blind. Interested parents with children who are blind or deaf-blind can contact Cindy at 227-7065.

SIBLINGS: Is There a Problem and What Do I Do About It

by Vicki M. Delaski, MS

An increasing amount of research on children who have siblings with disabilities is being done. Be it good or bad, I'm one of those people who don't always understand or trust all the statistics that come out of research. I want to know the bottom line...what does it all mean for my family and me?...how do I know if there is a problem?.....AND...what can I do to alleviate the problem once it is uncovered? I wrote this article for the people out there who are like me.

What does all the research mean to my family and me? When we examine our own sibling relationships we can get an idea of the general influence these relationships have on an individual. We, who have children with disabilities, are very aware of the effect that child has had on us as individuals and on the way we relate to other people, both in and outside our families. The research that has been done can help us better understand the effects this has on the brothers and sisters of these children. Not only on how it may effect them individually, but how it effects their relationship with the sibling with the disability as well as their relationships with others. The more we understand, the more we can help.

How do I know if there is a problem? Unfortunately, there are no one or two definite signs that are going to answer this questions. Each child is an individual and will display signs of stress, confusion, embarrassment, jealousy, resentment, anger, loneliness, guilt and fear in a different way. Tom may become aggressive when other children tease him about his brother, while Ann may become very introverted and shy. When there is a crisis at home, grades may go down or challenging behavior may go up. Watch, listen, and ask questions. Talk to them, their teachers, and their friends. Generally, be more involved in their lives and make it easier for them to come to you with issues and questions.

How do we help siblings communicate more openly? We all want to believe that our children will come to us if they have any problems or questions. The truth of the matter is, most children either don't know what to ask, how to ask, or are afraid that what they ask will make their parents feel bad, angry, disappointed or sad. The one thing they don't want to do is add to the problem or situation. Using the strategies above are some ways to accomplish this. Others include being more open and honest about our own feelings.

1. Talk about the disability and what it means for the whole family.
2. Schedule some special time with each sibling (use respite care to accomplish this).
3. Be fair as seen through the eyes of the siblings, not as seen through the eyes of an adult.
4. Evaluate your expectations for each child very carefully to allow each to be who they are meant to be.
5. Don't forget to let them be *just kids* once in a while.

Siblings need to talk about their feelings in a safe environment. That environment is viewed as safe using their eyes, not ours. It may not be at home or with peers, but with other siblings going through the same situations. Check with agencies in your area to see if there are any sibling support groups or if one could be started.

Vicki Delaski holds a Masters in counseling and facilitates sibling groups in Dayton, Ohio. She also works at St. Joseph Childrens Treatment Center with children who have severe behaviors and consults with the Dayton Public Schools regarding these children. She has a son with autism.

Reprinted from Perceptions, Vol 8, No 2, Summer 1994.

When asked what would constitute a quality life for their children with dual sensory impairments, parents listed the following major characteristics:

- A safe, comfortable, and stable home
- A social network of "people who care"
- Productive use of their time
- Engagement in work (e.g., paid employment, volunteer work, continued training, or leisure activities) that is personally meaningful, that enhances their self-image, and is valued by society
- Access to varied environments and activities that promote a full and interesting life
- Good health
- To be treated with dignity and worth

Giangreco, M. F., Cloninger, C. J., Mueller, P. H., Yuan, S., & Ashworth, S. (1991). Perspectives of parents whose children have dual sensory impairments. The Journal of the Association for Persons with Severe Handicaps, 14(1), 14-24.

Legal Briefs: What's the Big "IDEA?" Understanding the Individuals with Disabilities Education Act

by Joseph J. McNulty, Director
Helen Keller National Center

The reauthorization of the Individuals with Disabilities Education Act (IDEA) is the topic of discussion in the deaf-blind community today. It seems that each week brings a new rumor as to the changes we can expect and how they will affect children who are deaf-blind and their families.

The National Coalition on Deaf-Blindness gives a summary of what has happened in the past few months and what we will need to do between now and the Fall to protect the educational services currently being provided. In order to address the issues, it is important that we understand how the IDEA arrived at its present form.

Public Law 94-142, known as the Education of All Handicapped Children Act (EHA), was enacted in 1975 to establish grants to States for the education of children with disabilities. Acts such as the EHA are "authorized" for a fixed period of time, usually four and five years. As it nears the end of that time, Congress holds public hearings to determine whether or not the Act should be reauthorized. It is during these hearings that changes can be suggested to, hopefully, improve the piece of legislation.

An example of this occurred in 1986 when the EHA was amended by Public Law 99-457 to provide special funding incentives for States that would make a free, appropriate, public education available for all eligible preschool children with disabilities, ages three through five. Provisions were also included to help States develop early intervention programs for infants and toddlers with disabilities (this has become known as the Part H program). Another change took place in 1990 when the EHA was amended by Public Law 101-476, changing the name of the legislation to the Individuals with Disabilities Education Act.

The regulations for the IDEA define children with disabilities and include a listing of the types of disabilities these children might have. One is deaf-blindness. Deaf-blindness is among a very few disability categories with a separate authority under the IDEA - known as Part C, Section 622, Services for Children with Deaf-Blindness Program. This is the section of the Act that created the 307.11 Projects.

In the Winter 1994-95 issue of Deaf-*Blind Perspectives*, Dr. Judith Heumann, Assistant Secretary, Office of Special Education and Rehabilitation Services, U. S. Department of Education, wrote that,

"In many ways, the task of addressing the special needs of children who are deaf-blind has grown more difficult. Not only has there been a steady increase in the number of children identified as deaf-blind (9,873 in the latest data count, as of December 1993), but more children have other disabling conditions in addition to impaired hearing and vision. Further, we also face a much different situation than was experienced just a few years ago when more children were in separate schools. According to the December 1993 data count, approximately 78% of children who are deaf-blind are living with parents or extended family. Following the trend, more children who are deaf-blind are attending local schools. At the same time, the supply of qualified teachers needed to provide communication/language skills, orientation and mobility, and the other identified elements of a quality education program for children who are deaf-blind is critically limited . . . With such special learning needs, coupled with the critical shortage for trained personnel, the need for expert technical assistance has never been greater."

While Dr. Heumann's comments address the uniqueness of deaf-blindness and OSERS' attempt to meet the needs of children who are deaf-blind, **the recent actions of the Administration in no way support her statements**. As I mentioned earlier, reauthorization is viewed as an opportunity to review and improve a law. Among other things, the Administration's IDEA reauthorization proposal calls for the elimination of the thirteen disability categories that form the basis for who is eligible to be served under the IDEA. The Administration feels that the "labeling" of a child by his or her disability puts too much emphasis on the specific disability and not enough on the individual child's abilities and needs. In addition, giving students labels can stigmatize them and breed low expectations. The administration's recommendations include the amending of the current eligibility definition. A child would not need to be placed in any particular category so long as he/she was within the general functional definition.

This raises a serious question in my mind. **Are we being told that an appropriate education can be provided without knowing that the child is deaf-blind?**

Today's infrastructure, which is attempting to provide educational services to children who are deaf-

Legal Briefs: *(continued)*

blind, is not complete and we in the field are the first to admit that improvement is needed. As Dr. Heumann wrote, the task has grown more difficult, the number of children identified as deaf-blind is increasing, and there is a critical shortage of trained personnel. But there are good services being provided - it is a matter of increasing the funding of these programs to enable them to produce more teachers and provide additional technical assistance.

If we eliminate categorical or disability specific programs, have we improved the IDEA? Children who are deaf-blind will certainly still be in the education system. But, **how will we know how many there are, where they live or what services they need? How will parents ensure that their child is being taught by a qualified teacher? How many special ed/regular ed teachers have expertise in deaf-blindness? To whom do they turn for information and/or technical assistance when a child who is deaf-blind is enrolled in the class?**

The answers to these questions are quite apparent to me. I fully support the Administration's emphasis on the individual child and the need for us to recognize that students within a disability category have very different functional abilities and instructional needs. But I believe that we cannot begin to design an individualized program for a child or evaluate the appropriateness of such a program unless the vision and hearing problems are identified and addressed.

If we do not contact our elected officials regarding the elimination of the Services for Children with Deaf-Blindness Program, we will have lost all that has been gained over the past thirty years. Children who are deaf-blind will be served within the generic disability program and the existing specialized program for services to these children will no longer exist.

Reprinted from National Family Association for Deaf-Blind, Volume 1, Number 3, Spring 1995. Information in this article was taken from NICHCY News Digest, Vol. 1, No. 1, 1991 (IDEA) and Vol. 3, No. 2, Sept. 1993, (Legislative History of Special Ed.). For a thorough look at these articles, contact: NICHCY News Digest, P. O. Box 1492, Washington, DC 20013.

Never doubt that a small group of thoughtful committed citizens can change the world: Indeed, it's the only thing that ever has.

–Margaret Meade

To contact Alaska's officials regarding your comments about re-authorization of IDEA and services for children with deaf-blindness write:

Senator Ted Stevens
522 Hart Building
Washington, DC 20510-0201
(202) 224-3004 - Voice
(202) 224-2354 - FAX
(202) 224-1070 - TTY

Senator Frank H. Murkowski
706 Hart Building
Washington, DC 20510-0201
(202) 224-6665 - Voice
(202) 224-5301 - FAX
(202) 224-3685 - TTY

Congresman Don Young
2331 Rayburn Building
Washington DC 20510-0201
(202) 225-5765 - Voice
(202) 225-0425 - FAX

This newsletter was prepared by:

Sara J. Gaar and Marilyn A. Stack, Editors
Jan Fithian and Kitty Yawit - Production Specialists

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Conferences

What	National Conference for Active Learning: Turning Latent Potential into Dynamic Ability for Infant, Preschool, and Multi-Impaired Blind and Visually Impaired Children
When	June 19-23, 1995
Where	Novi, Michigan
Contact	Sherry Raynor, The Blind Children's Fund
Voice	517-333-1725
FAX	517-333-1730

What	Colorado Deafblind Institute
When	July 10-12, 1995
Contact	Tanni Anthony
Voice	303-866-6681
Contact	Jim Nezol
Voice	303-866-6719

.iat	International CHARGE Syndrome Conference
When	July 21-23, 1995
Where	Portland, Oregon
Contact	Lewis and Clark College
Voice	800-442-7604

What	Summer Institute, "A Path to Schools for the 21st Century"
When	July 31-August 4, 1995
Where	Bend, Oregon
Contact	Mary Anderson
Voice	503-378-3598 - ext. 640

What	Restructuring for Inclusion Summer Institute
When	August 6-11, 1995
Where	Eagle River, Alaska
Contact	Jenny Moore
Voice	907-465-8748
FAX	907-465-2166

What	Support Life 95, "More Stories of Inclusive Communities"
When	October 5-6, 1995
Where	Sacramento, California
ntact	Janis Lott or Ron Mainini
oice	916-263-1153

What	PATHWAYS Conference
When	October 13-15, 1995
Where	Anchorage, Alaska
Contact	P.A.R.E.N.T.S.
Voice	907-563-2246

What	Conference of Deafblindness; Living and Learning: A Lifelong Adventure
When	May 8-11, 1996
Where	Vancouver, British Columbia, Canada
Contact	Richmond Brit. Col. (call for papers)
Voice	604-668-7810
FAX	604-668-7812
	Submission due August 15, 1995

ON VACATION

For those interested in camps and recreational programs for children with disabilities, the listing below includes some resources.

Challenge Alaska offers a variety of activities such as sea kayaking, fishing, camping, hiking, rock climbing.
Fee: Sliding scale
Tel: 563-2658 in Anchorage or 790-2188 in Juneau

Easter Seals provides two, one-week camp sessions, in order to meet the varying needs of campers of different ages and disabilities. Staff includes adaptive recreation specialists, educators, sign language interpreters, skilled expedition leaders, artists and supportive assistant counselors.
Dates: July 23-29 and August 6-12
Fee: $300
Tel: 277-7325

Alpine Alternatives provides various camp experiences specific to the needs of the campers. Overnight camps, day outings and an equestrian program are available.
Dates: Overnight camps are July 5-9, August 13-18 and August 20-26. Day outings begin June 19.
Fee: Varies
Tel: 561-6655

(continued on page 8)

On Vacation *(continued)*

Alaska Independent Blind provides a camp for blind and visually-impaired children. Activities offered include fishing, hiking, canoeing, swimming, campfires, nature walks, horseback riding.
Dates: July 30-August 5
Fee: Free
Tel: 563-2525 or (800) 478-9998

Municipality of Anchorage, Parks and Recreation Therapeutic Recreation offers a variety of classes including swimming, music, arts and crafts.
Tel: 561-0108

Rainbow Connection provides a therapeutic riding program in Anchorage.
Tel: 346-3402

Solid Rock Bible Camp offers a camp for children, ages 7-17, with disabilities.
Dates: June 7-11
Fee: Free
Tel: 262-4741

My Sister

By Adrienne D'Luna, Age 9

Some say she can't see, others say "Poor thing."
Doctors say she can't hear, but...
I know she has improved so much,
I know what she can do, not what she can't.
I've watched her write her name,
I've heard her sing a song from a year and a half ago.
I've watched her pretend.
I've seen her happy.
I know her, as most people don't.
I know she can see me,
I know she can hear me,
She is so happy and gets such a big thrill out of so many tiny things.
How wonderful it is to see her progress.
I love it when I read to her, she loves it when I do;
And sometimes when I read her a simple book, she reads it back to me.
I would be such a different person without her,
I would not know how to sign or be so understanding.
Even though I can see and hear as most all the world does,
It is better for me, because of her.
I love her, my sister Alexis.

From reSources, October 1994; California Deaf-Blind Services.

Special Education Service Agency
2217 East Tudor Road - Suite 1
Anchorage, AK 99507

Please Share

Alaska

Services for Children and Youth with Dual Sensory Impairment

Referral Packet
1995-96

SPECIAL EDUCATION SERVICE AGENCY

2217 EAST TUDOR ROAD, SUITE 1 / ANCHORAGE, ALASKA 99507 / PHONE (907) 562-7372 / FAX (907) 562-0545

Alaska Services For Children and Youth with Dual Sensory Impairments

What is Alaska Services for Children and Youth with Dual Sensory Impairments (DSI)?

The DSI program is federally funded under the Individuals with Disabilities Act (IDEA) to provide technical assistance for individuals, ages birth through 21 years, who have *both* a vision and hearing loss. These services are in addition to those provided by schools and other state and local agencies.

Why DSI Services?

Having a combined hearing and vision loss is considered a low incidence disability because of its rarity. The effect of a dual sensory impairment can create unique needs in communication, mobility and overall learning requiring specialized supports and interventions. The DSI program provides technical assistance to service providers and families in addressing the unique needs of learners with deaf-blindness.

Who is Eligible for DSI Services?

Children and youth (birth through 21 years of age) eligible to receive services through the DSI program have a combined vision and hearing loss. The combined effects of both of these sensory losses, even if both are mild, may qualify the child for the DSI program.

Who Can Refer?

Referrals may be made by parents as well as educational, medical, or social service agencies.

How Are Referrals Made?

Referrals are made by contacting the DSI program and letting us know about the child. A formal referral packet will then be mailed. This packet includes:

1. Information about the DSI program
2. *Initial Student Referral* form
3. *Authorization for Mutual Exchange of Information* form
4. Please return the referral form and the information exchange form with:
   a. Medical documentation of an identified or suspected hearing and vision loss, and
   b. current IEP or IFSP.

A NON-PROFIT CORPORATION PROVIDING EDUCATIONAL SERVICES

SPECIAL EDUCATION SERVICE AGENCY

2217 EAST TUDOR ROAD, SUITE 1 / ANCHORAGE, ALASKA 99507 / PHONE (907) 562-7372 / FAX (907) 562-0545

Alaska Services for Children and Youth with Dual Sensory Impairments

Special Education Service Agency (SESA) is the recipient of federal funds under the Individuals with Disabilities Education Act (IDEA) to provide services for children and youth, ages 0-21 years who have both vision and hearing impairments. The Dual Sensory Impairment (DSI) Program services are provided at no cost and are in addition to those provided by schools and infant learning programs.

The purpose of the DSI Program is to assist service providers and families in preparing learners with dual sensory impairments for quality lives in their communities. Some of the activities provided by the DSI Program include:

Technical Assistance to service providers and families through personalized on-site consultation, inservice training, workshops, and assistance with program design and development.

Information Dissemination regarding deaf-blindness is available concerning local, state, and national resources. The DSI newsletter, *Keeping In Touch*, and program mailings provide up-to-date information. The SESA library maintains current literature and videotapes specific to deaf-blindness.

Collaboration with other technical assistance projects and programs such as TRACES Technical Assistance Project, Helen Keller Technical Assistance Center, and Hilton-Perkins provides additional opportunities for expanding training and technical assistance.

Assistance In Identifying children with dual sensory-impairments is available through functional assessments, trainings, workshops, and other activities.

Family Support Activities are available to DSI Program families. Activities include family weekend retreats and participation in family conferences.

If you have any questions or would like additional information, please contact Sara J. Gaar, program supervisor, at (907) 562-7372.

jf:7/95

A NON-PROFIT CORPORATION PROVIDING EDUCATIONAL SERVICES

Alaska Services for Children and Youth with Dual Sensory Impairment

The term "dual sensory impairment" refers to individuals who experience <u>both</u> vision and hearing impairments. The combined effects of both of these sensory losses, even if both are mild, may qualify him or her as deaf-blind or dual sensory impaired.

Consideration for Referral to the Dual Sensory Impairment Program

Vision

1. Visual acuity of 20/70 or less in the better eye with correction as determined by an eye specialist (i.e., 20/100, 20/200, etc.).
2. Visual field restriction of 20 degrees or less ("tunnel vision").
3. Functional vision which is virtually absent or unmeasurable for purposes of learning as indicated by an eye specialist.
4. A need for special services requiring the use of non-standard instructional materials or aids designed to facilitate the child's learning as recommended by an eye specialist.
5. A temporary impairment or loss of vision due to such factors as illness, accidents, temporary treatments.
6. A diagnosis of a syndrome or disorder associated with a progressive vision loss.

and

Hearing

1. Unaided hearing impairment of 30dB or greater.
2. Recurrent otitis media or a documented history of otitis media effecting language or learning abilities.
3. Functional hearing which is virtually absent or unmeasurable for purposes of learning, as indicated by a hearing specialist or speech-language pathologist.
4. A diagnosis of a syndrome or disorder associated with a progressive hearing loss.

Services Available

- Assistance in identification.
- On-site technical assistance (e.g., training, consultation, and collaboration, inservice workshops, assistance in program design) for families, educators and other service providers.
- Lending library with up-to-date books, articles and manuals.
- Access to programs, professionals, and parents who are involved with individuals who are deaf-blind and their families.
- Newsletters and program mailings for up-to-date materials on deaf-blindness.

jf:9/95

SPECIAL EDUCATION SERVICE AGENCY
2217 E. Tudor Rd., Suite 1, Anchorage, Alaska 99507
Phone: (907) 562-7372 FAX: (907) 562-0545

SESA Use Only
Date received:_____
Date district notified_____ P F M
Eligible: Yes___ No____
Wo made contact?_____
Specialist Assigned:_____
VI___ O&M___ Both___

INITIAL REFERRAL

1. Student Name: _____ Grade: _____ Date of Birth: _____

   District: _____ School (Village): _____

   Special Education
   Director/Coordinator: _____ Teacher: _____

2. **STATE CLASSIFICATION OF STUDENT**: *Check the space which indicates the state classification for the student.*

   _____ Vision Impairment
   _____ Deaf
   _____ Hard of Hearing
   _____ Dual Sensory Impairment (Deaf/Blind)
   _____ Orthopedic Impairment
   _____ Autism
   _____ Mental Retardation
   _____ Other Health Impairment
   _____ Behavior Disorder/Serious Emotional Disturbance
   _____ Multiple Disabilities
   _____ Traumatic Brain Injury
   _____ Preschool Developmental Disabilities

3. **Please attach the following** available information to assist SESA:

   - Copy of current IEP or IFSP for Preschool Developmental Disability
   - Academic level
   - Developmental level
   - Communication level
   - Social history

4. ASSISTANCE REQUESTED

   Please check the service area or areas for which you are requesting assistance (service request may be in an area which is different from state classification). Current documentation as specified below must accompany this Referral form.

DISABILITY	DOCUMENTATION NEEDED
_____ Preschool Disabilities	Supporting information for state classification
_____ Vision Impairment	Eye report from ophthalmologist/optometrist, SESA questionnaire
_____ Deaf/Hard of Hearing	Recent audiogram from audiologist, SESA questionnaire
_____ Orthopedic Impairment	Medical report
_____ Other Health Impairment	Medical report
_____ Behavior Disorder/Serious Emotional	Psychological report, Adaptive Behavior Scale Disturbance
_____ Multiple Disabilities	Eye, audiological, medical, and/or psychological reports specific reports specific to the disabilities
_____ Dual Sensory Impairment (Deaf-Blind)	Vision report and audiogram
_____ Mental Retardation	Psychological report including results of the Adaptive Behavior Scale and IQ score
_____ Autism	Psychological report, Adaptive Behavioral/Social Scale, communication evaluation
_____ Traumatic Brain Injury	Medical, therapy, speech/language & psychological reports

5. **An Authorization of Mutual Exchange of Information** form must also be completed and returned with this Initial Referral form. Please insure that that form contains your district name, all agencies with which information may be exchanged, and the parent's signature.

6. _____ _____
   Signature of District Special Education Coordinator *Date of Referral*

jf:8/94

SPECIAL EDUCATION SERVICE AGENCY

2217 EAST TUDOR ROAD, SUITE 1 / ANCHORAGE, ALASKA 99507 / PHONE (907) 562-7372 / FAX (907) 562-0545

Parent Permission for SESA Consulting Services
and
Mutual Exchange of Information

I give my permission for a SESA consultant to provide technical assistance services to the school district regarding the educational program for my my son/daughter :

_____ _____
Name of Student *Student's Date of Birth*

SESA assistance includes but is not limited to:

- classroom observations
- teacher/parent consultations
- demonstration and training in specialized strategies
- assistance in development and implementation of instructional and behavioral intervention

I also give my permission for a mutual exchange of information between SESA and the _____ School District and between SESA and the following organizations/individuals:

1. _____
_____
_____

2. _____
_____
_____

3. _____
_____
_____

4. _____
_____
_____

I understand that all practices of confidentiality will be followed in the use of information gathered. This release is valid for three years from the date it is signed.

_____ _____
Signature of Person Giving Consent *Date*

_____ _____
Relationship to Student *Address*

_____
Phone

A copy of this form may be sent to each agency/person listed. If you do NOT wish all agencies listed to receive this please advise on the back of this form.

jf:7/95

Information

about

USHER SYNDROME

Usher syndrome is a genetic disorder involving the loss of both sight and hearing. The hearing loss generally occurs at birth or shortly thereafter, while a progressive loss of vision due to retinitis pigmentosa (RP) begins later in life, **usually before adolescence.** RP is degeneration of the retina of the eyes. The vision loss may be gradual and barely noticeable at first. There is no way of knowing the time of onset or rapidity of vision loss, but in almost all cases the result is legal blindness.

While only approximately 4 in 100,000 people are diagnosed with Usher syndrome, it is estimated that **3 to 6 percent of people who have an hereditary hearing loss have the condition.** It has been reported that Usher syndrome accounts for more than 50 percent of all cases of deaf-blindness, with 94,000 estimated to be affected in the United States.

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As of Fall 1993, there are no individuals in Alaska, ages 0 to 21, identified with Usher syndrome.

Ninety percent of individuals with Usher syndrome have one of two main types:

Type I Profound hearing loss present at birth
Balance problems
Retinitis pigmentosa (RP)

Type II Mild to severe hearing loss present at birth or shortly after
No balance problems
Retinitis pigmentosa (RP)

Those **at risk** for Usher syndrome are born with a hearing loss. The hearing loss is sensorineural, or "nerve deafness." The vision loss due to RP occurs later. By screening for a vision loss, Usher syndrome can be diagnosed at the earliest possible time. RP manifests itself in increasing difficulty seeing in the dark or to the side (peripheral vision). Vestibular problems, such as poor balance, may be present.

Following are some behavioral symptoms which may indicate Usher syndrome and can be used for basic screening.

<u>Night Blindness</u>

- Can't see when coming in from bright sunlight
- Trips over things when light changes or light is dim
- Stays near light in a dark room or at night
- Positions oneself so light falls on face of a speaker
- May express a desire to enter a room before it is darkened (e.g. movie theater)
- Avoids conversations in a darkened area
- May appear to stagger or lose balance after an oncoming car has passed at night
- Has problems reading under some lights or in dimly lit areas

What Are Symptoms Suggesting Usher Syndrome?

Restricted Visual Field

- Stumbles on stairs and curbs
- Bumps into people, tables and chairs
- May have accidents at mealtime with objects placed to the side
- Startles easily
- Seems to hold eyes in different directions when looking at some things
- Turns head while reading across a page
- Uses fingers to mark place while reading
- Can't find small objects that have been dropped
- Fails to glance at another person's hand waving from the side
- Is quiet or may edge to one side when in a large group
- Frequently misses or fails to understand group instruction

Glare Sensitivity

- Squints and shades eyes in bright lights or fluorescent lighting
- Likes to wear sunglasses even in a building, but especially in bright sunlight
- May appear awkward when exiting from a building (when faced with bright lights)

Needs Contrast

- Has difficulty reading light copies or ditto copies
- Can't see stars at night
- Often spills when pouring liquids

Problems with Acuity

- Holds book close to eyes, or bends to read
- Sits near blackboard

Balance Problems

- Late learning to walk (past 15 months)
- Is considered clumsy
- Loses balance easily in dark
- Can't ride a bicycle or required a long time to learn

Other

- Is frequently last in completing group activities
- Exhibits anxiety in new areas
- Often last to enter a room
- May have repetitive behavior or routines at particular times
- May fail to participate fully in group activities associated with new situations in the dark
- Frequently hesitates at the top or bottom of the stairs
- Avoids walking or running in unfamiliar areas, especially when there is bright sunlight or in a darkened area
- Constantly appears to be visually scanning a group

Individuals with Usher syndrome may often be the first to notice the subtle changes associated with gradual visual loss. Questions such as those listed below may help the family, teacher or school nurse acquire the information needed for a basic screening.

Ask the individual:

When you walk inside a dark movie theater or room, do you have a hard time seeing seats and people?

When you come inside from a bright, sunny day, can you see things and people?

Do you trip over things?

Does sunlight hurt your eyes?

Do you often spill liquids when pouring them into a cup or glass?

Can you see stars in the sky at night?

If someone waves to you from the side, do you see them when you are not looking at them?

Is it hard to find small objects when you drop them on the floor?

Do you bump into people, chairs, things?

Do you have trouble riding a bicycle?

Do you sometimes knock over a glass of water or other object on the table at mealtimes?

What Are Symptoms the Individual May Notice?

Early identification of Usher syndrome is crucial because:

1) The individual, parents and teachers can plan for education, vocational experiences and guidance, taking into account eventual visual difficulties.

2) The gradual decrease in vision may be unnoticed by the individual, who may continue activities (such as driving or working in hazardous conditions) that cannot be continued safely.

3) A diagnosis of Usher syndrome allows parents and children to consider genetic counseling and testing for other children in the family.

4) The individual can receive counseling and support to prepare him or her for the future.

Why is Early Identification Crucial?

Several tests are used to determine whether a person has retinitis pigmentosa (RP). Some types of screening can be completed by a teacher or other interested adult. These screenings will be explained in more detail in the following pages.

Some tests can be completed by most eye specialists during a regular exam. These tests include a visual field test to assess side vision, psychophysical testing to evaluate color and contrast vision, and dark adaptation testing. However, the definitive test for RP is electroretinography (ERG), which has been found to be 95 percent accurate. ERG testing is available at many medical centers outside of Alaska, but is available in Alaska at only one location (please see Resources).

ERG is the measurement of the electricity given off by nerve impulses in the retina of the eye. The test, which is generally painless, is done by having the patient wear special contact lenses while looking at a flashing light. This test is usually administered by an ophthalmologist.

The first noticeable symptom of Usher syndrome is a sensorineural hearing loss at birth or shortly after birth. If the hearing loss is a result of any of the conditions listed below, the person is at **low risk** for Usher syndrome. There is always a small chance that there is a secondary cause of the hearing loss, which **may** be Usher syndrome, but this is extraordinarily rare.

- **conductive loss**
- **kidney disease**
- **trauma/accident**
- **genetic deafness ***
- **auditory neuritis**
- **Diabetes**
- **viral infection**
- **disease (Meningitis, Mumps, Scarlet Fever, Measles, Chicken Pox, Encephalitis)**
- **Rubella (German measles)**
- **Otitis media (ear infections)**
- **scarring of the eardrum**
- **noise-induced loss**
- **ototoxic drug therapy**
- **other known syndromes (please name _____)**

*** The genes for hereditary deafness and for Usher syndrome are different. A person at risk for Usher syndrome probably will not have a family member experiencing deafness (unless they too have Usher syndrome). More than likely they will be the only family member with a hearing loss.**

While people experiencing a hearing loss due to any of the conditions listed are at <u>low risk</u> for Usher syndrome, they may suffer vision loss for other reasons. This makes it important to have comprehensive, regular eye exams.

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The first step in an effective screening is to eliminate those individuals at low risk for Usher syndrome. Then, with the use of the previous behavior checklist, subtle changes may be noticed which may signal vision loss. The next step is the need for further screening and referral to an eye doctor.

After checklists are completed, the school nurse or teacher can carry out further screening, including dark adaptation and visual field testing. Individuals losing their vision due to RP will begin to experience night blindness, field loss, and eventually central vision loss.

Dark adaptation test: Since RP usually begins to manifest itself as the inability to see well in dim lighting or darkness, this is the most basic preliminary test. The test should be done in a completely darkened room. Place a few items around the room. Ask the individual to sit in the dark room for about six minutes to allow his eyes to adjust to darkness. Then ask him or her to walk around the room. Observe if he/she bumps or stumbles into objects or walls. This is a crude test and does not necessarily indicate the individual has RP. The ophthalmologist or optometrist has a more sophisticated dark adaptation test.

Field testing: The visual field loss associated with RP is a progressive condition which develops slowly. Screening should take place yearly, since the loss may not be noticed until it becomes severe. The field loss might initially occur first as a circular or "doughnut" shaped area of loss.

To test for a field loss, test one eye at a time (the loss may be different in each eye). Facing the individual to be examined, the examiner has the subject cover one eye with his or her hand. After giving instructions to look straight ahead at the examiner's nose, the examiner holds one or two fingers up off to the side, just within his or her own visual field. Then the individual is asked whether he or she can see one or two fingers. This is repeated on the other side. If the individual is able to discriminate between one or two fingers, using the examiner's field of vision as a standard, it is evident that there is not a significant loss of visual field.

If any vision problem is observed during the use of the checklists (see Screening Forms in back of brochure) and vision screening tests mentioned above, refer the child to an ophthalmologist to test for retinitis pigmentosa. The definitive test, electroretinography (ERG), may need to be repeated several times to confirm or disprove the diagnosis.

Retinitis pigmentosa develops gradually. Screening for children at risk should occur yearly until the child leaves school unless there is some other evidence, through ophthalmological testing, that the child does not have Usher syndrome.

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Vision is particularly important to all deaf and hard-of-hearing individuals. Children with hearing losses should have regular eye exams by an optometrist or ophthalmologist whether or not they are at risk for Usher syndrome.

The eye doctor may not routinely test for field loss. This screening and other tests should be requested during the basic exam.

Make sure the following are included in the complete eye exam:

* a dilated eye exam
* field testing
* contrast and color sensitivity testing
* dark adaptation testing

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If the child exhibits symptoms on the checklist or during school screening, it is critical that further testing be done. An ophthalmologist or optometrist will complete psychophysical testing to evaluate color vision, contrast testing, dark adaptation testing and a visual field test.

While many ophthalmologists or optometrists can do preliminary screening, they will need to refer the individual for more definitive testing with the ERG. As noted, there is currently only one ERG in Alaska. Dr. Arnold and Dr. Harrison can be contacted regarding ERG testing.

Once the diagnosis of Usher syndrome is confirmed, planning can take place for the child and family.

For more information on Usher syndrome and on resources available to assist individuals with Usher syndrome, contact the physicians named below or any of the agencies listed on the next two pages.

Dr. Robert W. Arnold, M.D.
542 West Second Avenue
Anchorage, AK 99501-2242
(907) 276-1617

Dr. Thomas J. Harrison, M.D.
3500 LaTouche, Suite 250
Anchorage, AK 99508
(907) 561-1530

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Local Resources

Alaska Services for Children and Youth
with Dual Sensory Impairments
2217 E. Tudor Rd., Suite 1
Anchorage, AK 99507
(907) 562-7372 (voice)
(907) 563-8284 (TDD)
(907) 562-0545 (FAX)

Deaf-Blind Affiliation Program
620 E. 10th, Suite 302
Anchorage, AK 99501
(907) 258-0500 (voice)
(907) 258-0510 (TDD)
(907) 279-0341 (FAX)
(800) 770-0501

National Information Resources

American Association of the Deaf-Blind (AADB)
814 Thayer Avenue
Silver Spring, MD 20910
(301) 588-6545

Boys Town National Research Hospital
Usher Syndrome Project
555 North 30th Street
Omaha, NE 68131
(402) 498-6556 (voice)
(402) 498-6631 (TDD)
(800) 835-1468 (voice/TDD)

RP Foundation Fighting Blindness
1401 Mt. Royal Avenue, 4th Floor
Baltimore, MD 21217
(410) 225-9400 (voice)
(410) 225-9409 (TDD)
(800) 683-5555

Helen Keller National Center for Deaf-Blind Adults
111 Middleneck Road
Sands Point, NY 11090
(516) 944-8900 (voice/TDD)

Helen Keller National Center for Deaf-Blind Adults
Northwest Region
2366 Eastlake Ave. E, Suite 209
Seattle, WA 98102
(206) 324-9120 (voice/TDD)

Hearing and Vision Impaired Program
Gallaudet University
800 Florida Ave. NE
Washington, D.C. 20002
(202) 651-5096 (voice/TDD)

The following forms are for your use in screening:

1. Family Questionnaire
2. Low Risk Causes
3. Behavioral Screening

Name of child: _____ Age: _____
Date: _____

Family Questionnaire

The information you provide on this form will be used by the school in vision screening of your child. Please complete it to the best of your knowledge and return it to the school.

1. Is there any known hereditary deafness (hearing impairment) in the family (parents, siblings, cousins, etc.)? If yes, please explain.

_____
_____
_____
_____

2. Are there any known cases of hereditary blindness (vision impairment) in the family? If yes, please explain.

_____
_____
_____
_____

3. Does your child have a congenital (existing from birth) hearing loss? If yes, please explain.

_____
_____
_____
_____

4. What is the cause of your child's hearing loss?

_____
_____

USHER SYNDROME SCREENING
Low Risk Causes

NAME: _____

Birth Date: _____ Current Date: _____

Completed by: _____

Etiology (cause) of hearing loss/deafness:

_____

_____

_____

_____

Please check, if applies:

____ conductive loss
____ kidney disease
____ trauma/accident
____ genetic deafness
____ auditory neuritis
____ Diabetes
____ viral infection
____ disease (Meningitis, Mumps, Scarlet Fever, Measles, Chicken Pox, Encephalitis)
____ Rubella (German measles
____ Otitis media (ear infections)
____ scarring of the eardrum
____ noise-induced loss
____ ototoxic drug therapy
____ other known syndromes (please name _____)

If the hearing loss is a result of any of the conditions listed above, the person is at **low risk** for Usher syndrome. There is always a small chance that there is a secondary cause of the hearing loss, which **may** be Usher syndrome, but this is extraordinarily rare.

Please place this sheet in student's folder

BEHAVIORAL OBSERVATIONS
for Usher Screening

Name: _____

Birth Date: _____ **Current Date:** _____

Completed by: _____

Night Blindness

____ Can't see when coming in from bright sunlight
____ Trips over things when light changes or light is dim
____ Stays near light in a dark room or at night
____ Positions oneself so light falls on face of a speaker
____ May express a desire to enter a room before it is darkened (e.g. movie theater)
____ Avoids conversations in a darkened area
____ May appear to stagger or lose balance after an oncoming car has passed at night
____ Has problems reading under some lights or in dimly lit areas

Restricted Visual Field

____ Stumbles on stairs and curbs
____ Bumps into people, tables and chair
____ May have accidents at mealtimes with objects placed to the side
____ Startles easily
____ Seems to hold eyes in different directions when looking at some things
____ Turns head while reading across a page
____ Uses fingers to mark place while reading
____ Can't find small objects that have been dropped
____ Fails to glance at another person's hand waving from the side
____ Is quiet or may edge to one side when in a large group
____ Frequently misses or fails to understand group instruction

Glare Sensitivity

____ Squints and shades eyes in bright lights or fluorescent lighting
____ Likes to wear sunglasses even in a building, but especially in bright sunlight
____ May appear awkward when exiting from a building (when faced with bright lights)

Needs Contrast

____ Has difficulty reading light copies or ditto copies
____ Can't see stars at night
____ Often spills when pouring liquids

Problems with Acuity

____ Holds book close to eyes, or bends to read
____ Sits near blackboard

Balance Problems

____ Late learning to walk (past 15 months)
____ Is considered clumsy
____ Loses balance easily in dark
____ Can't ride a bicycle or required a long time to learn

Other

____ Is frequently last in completing group activities
____ Exhibits anxiety in new areas
____ Often last to enter a room
____ May have repetitive behavior or routines at particular times
____ May fail to participate fully in group activities associated with new situations in the dark
____ Frequently hesitates at the top or bottom of the stairs
____ Avoids walking or running in unfamiliar areas, especially when there is bright sunlight or in a darkened area
____ Constantly appears to be visually scanning a group

If several items are marked throughout the whole checklist, the individual should receive further testing. Refer to the "Dark Adaptation Test" and "Field Testing" found in the Screening section of this pamphlet. Any suspicions should be medically evaluated by an ophthalmologist or optometrist.

This brochure was adapted from the Illinois Usher Syndrome Screening Project.

Funding for the Alaska Usher Syndrome Project is from the following: Alaska State Division of Vocational Rehabilitation; Helen Keller National Center; TRACES; and the U.S. Department of Education.

In addition, thank you to the many reviewers who contributed to the development of this brochure.

Alaska Center for Blind and Deaf Adults
Deaf-Blind Affiliation Program
and
Special Education Service Agency
Alaska Services for Children and Youth
with Dual Sensory Impairments

Acknowledgements

October 1993

USHER SYNDROME

Screening Forms

Alaska Center for Blind and Deaf Adults
Deaf-Blind Affiliation Program
and
Special Education Service Agency
Alaska Services for Children and Youth
with Dual Sensory Impairments

NAME: _____

Birth Date: _____

USHER SCREENING FORMS

Dates

1. **Family Questionnaire**
   completed? ..... _____
2. **Low Risk Causes**
   low risk? ..... _____
3. **Behavioral Observations**
   number failed? ..... _____
4. **Dark Adaptation Screening**
   visually adapts? ..... _____
5. **Field Screening**
   discriminates peripherally? ..... _____
6. **Additional Comments**

Y = yes
N = no

Name of Child: _____ **Current Date:** _____

Birth Date: _____

Completed by: _____

Family Questionnaire

The information you provide on this form will be used by the school in vision screening of your child. Please complete it to the best of your knowledge and return it to the school.

1. Are there any known blood relatives in the family (parents, brothers, sisters, cousins, etc.) who have a hearing loss? If yes, please describe their hearing loss and cause, if known.

_____

_____

_____

2. Are there any known cases of blood relatives who have trouble seeing at night? If yes, please explain.

_____

_____

_____

3. Does your child have a congenital (existing from birth) hearing loss? If yes, please explain.

_____

_____

_____

4. What is the cause of your child's hearing loss?

_____

_____

_____

USHER SYNDROME SCREENING
Low Risk Causes

NAME: _____

Birth Date: _____ Current Date: _____

Completed by: _____

Etiology (cause) of hearing loss/deafness:

_____

_____

_____

Please check, if applies:

_____ conductive loss
_____ kidney disease
_____ trauma/accident
_____ genetic deafness
_____ diabetes
_____ viral infection disease (meningitis, mumps, scarlet fever, measles, chicken pox, encephalitis)
_____ rubella (German measles)
_____ otitis media (ear infections)
_____ noise-induced loss
_____ ototoxic drug therapy
_____ other known syndromes (please name _____)

If the hearing loss is a result of any of the conditions listed above, the person is at **low risk** for Usher syndrome. There is always a small chance that there is a secondary cause of the hearing loss, which **may** be Usher Syndrome, but this is extraordinarily rare.

BEHAVIORAL OBSERVATIONS
for Usher Screening

NAME: _____

Birth Date: _____ **Current Date:** _____

Completed by: _____

Night Blindness

_____ Can't see when coming from bright sunlight
_____ Trips over things when light changes or light is dim
_____ Stays near light in a dark room or at night
_____ Positions oneself so light falls on face of a speaker
_____ May express a desire to enter a room before it is darkened (e.g., movie theater
_____ Avoids conversations in a darkened area
_____ May appear to stagger or lose balance after an oncoming car has passed at night
_____ Has problems reading under some lights or in dimly lit areas

Restricted Visual Field

_____ Stumbles on stairs and curbs
_____ Bumps into people, tables and chairs
_____ May have accidents at mealtimes with objects placed to the side
_____ Startles easily
_____ Seems to hold eyes in different directions when looking at some things
_____ Turns head while reading across a page
_____ Uses fingers to mark place while reading
_____ Can't find small objects that have been dropped
_____ Fails to glance at another person's hand waving from the side
_____ Is quiet or may edge to one side when in a large group
_____ Frequently misses or fails to understand group instruction

Glare Sensitivity

_____ Squints and shades eyes in bright lights or fluorescent lighting
_____ Likes to wear sunglasses even in a building, but especially in bright sunlight
_____ May appear awkward when exiting from a building (when faced with bright lights)

Needs Contrast

_____ Has difficulty reading light copies or ditto copies
_____ Can't see stars at night
_____ Often spills when pouring liquids

Problems with Acuity

_____ Holds book close to eyes, or bends to read
_____ Sits near blackboard

Balance Problems

_____ Late learning to walk (past 15 months)
_____ Is considered clumsy
_____ Loses balance easily in dark
_____ Can't ride a bicycle or required a long time to learn

Other

_____ Is frequently last in completing group activities
_____ Exhibits anxiety in new areas
_____ Often last to enter a room
_____ May have repetitive behavior or routines at particular times
_____ May fail to participate fully in group activities associated with new situations in the dark
_____ Frequently hesitates at the top or bottom of the stairs
_____ Avoids walking or running in unfamiliar areas, especially when there is bright sunlight or in a darkened area
_____ Constantly appears to be visually scanning a group

If several items are marked throughout the whole checklist, the individual should receive further testing. Refer to the "Dark Adaptation Test" and "Field Testing". Any suspicions should be medically evaluated by an ophthalmologist or optometrist.

NAME: _____

Birth Date: _____ Current Date: _____

DARK ADAPTATION SCREENING

Procedure:

Have the student sit in a darkened room for about six minutes, which typically is enough time for the eyes to adjust to the darkness. Then ask him or her to walk around the room. Observe if he or she bumps or stumbles into objects.

Results:

_____ able to ambulate in the dark without problems

_____ has difficulty ambulating in the dark

NAME: _____

Birth Date:_____ Current Date:_____

FIELD SCREENING

Procedure:

The examiner should face the student and have the student cover one eye with his or her hand. After giving instructions to look straight ahead at the examiner's nose, the examiner holds one or two fingers up off the side, must within his or her own visual field. The student is then asked whether he or she can see one or two fingers. This is repeated on the other side. If the student is able to discriminate between one or two fingers, using the examiner's field of vision as a standard, it is evident that there is not a significant loss of visual field. Each eye should be tested individually, as there might be a loss difference in each eye.

Results:

Peripheral Discrimination

_____ Left eye

_____ Right eye

kv:7/94

Parent

esource

Guide

BEST COPY AVAILABLE

State Agencies, Groups and Organizations

Name: AK Services for Children & Youth with Dual Sensory Impairments Contact Person: Sara Gaar or Marilyn Stack Phone: 562-7372 Address: 2217 E. Tudor Rd., Suite 1 Anchorage, AK 99507	Comments
Name: Contact Person: Phone: Address:	Comments
Name: Contact Person: Phone: Address:	Comments
Name: Contact Person: Phone: Address:	Comments
Name: Contact Person: Phone: Address:	Comments

"Knowledge can be communicated, but not wisdom."
—Herman Hesse

Schools

Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

"Character—the willingness to accept responsibility for one's own life—is the source from which self-respect springs."
—Joan Didion

Parents

Name: **Phone:** **Address:**	**Comments**
Name: **Phone:** **Address:**	**Comments**
Name: **Phone:** **Address:**	**Comments**
Name: **Phone:** **Address:**	**Comments**
Name: **Phone:** **Address:**	**Comments**

There are three ways to get something done: do it yourself, hire someone, or forbid your kids to do it.
—*Monta Crane*

Transition Services

Name: Deaf-Blind Affiliation Program **Contact Person:** Marcia Barnes **Phone:** 258-0500 **Address:** 630 E. 10th St., 302 Anchorage, AK 99501-3708	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

Success comes before work only in the dictionary.

Medical and Health Services

Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

Don't rely on child-resistant packaging to prevent accidental poisonings. Child-resistant does not mean child-proof. Out of sight and out of reach is the best prevention.

Personal Resources

Name: **Phone:** **Address:**	**Comments**
Name: **Phone:** **Address:**	**Comments**
Name: **Phone:** **Address:**	**Comments**
Name: **Phone:** **Address:**	**Comments**
Name: **Phone:** **Address:**	**Comments**

I do not want the peace which passeth understanding. I want the understanding which bringeth peace.
—Helen Keller, 1880-1968

Parent Organizations

Name: PARENTS, Inc **Contact Person:** **Phone:** 1-800-478-7678 **Address:** 540 W. International Airport Rd., Suite 200 Anchorage, AK 99518	**Comments**
Name: National Association for Parents of the Visually Impaired (NAPVI) **Contact Person:** **Phone:** 1-800-562-6265 **Address:** 2128 Linway Drive Beloit, WI 53511-2720	**Comments**
Name: Alaska Alliance Deaf Children **Contact Person:** **Phone:** 333-4351 **Address:** 1345 Rudakoff Circle Anchorage, AK 99504	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

The great education of life is not knowledge, but action.
—Thomas Henry Huxley

National Agencies, Groups, and Organizations

Name: D-B Link **Contact Person:** **Phone:** 1-800-438-9376 **Address:** Perkins School for the Blind 175 N. Beacon Street Watertown, MA 02172	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

The object of education is to prepare the young to educate themselves throughout their lives.
—*Robert Maynard Hutchins*

Respite Services

Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

It is better to light a candle than to curse the darkness.
—CHINESE PROVERB

Community and Local Services

Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

When you get right down to the root meaning of the word "succeed," you find that it simply means to follow through.
—F. W. Nichol

Financial Assistance

Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

The value of a dollar is social, as it is created by society.
—Emerson, 1860

Legal and Protective Services

Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

The law is a causeway upon which, so long as he keeps to it, a citizen may walk safely..
—Robert Bolt

Recreational Services

Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**
Name: **Contact Person:** **Phone:** **Address:**	**Comments**

Laughter is a tranquilizer with no side effects.
—Arnold Glasow

Notes

END